Improving Person-centred Care for Hospice Patients who have Difficulty Expressing their Needs

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**Summary of project**

A significant number of palliative care patients have difficulty communicating their needs, which may be a result of dysphasia, cognitive impairment or extreme frailty. The aim of this project was to support hospice staff to provide person-centred care and improve symptom management for these patients.

The project team comprised a multidisciplinary group of hospice staff, an already established group interested in meeting the needs of people experiencing cognitive impairment. The project was developed in two phases. Phase one aimed to support nursing staff to develop a general level of skills to understand patients with difficulty expressing their needs and to avoid or relieve unwarranted distress. Phase two looked to provide multidisciplinary staff with specific skills in supportive and augmentative communication techniques and the use of a behavioural assessment tool. This report discusses phase one of the project.

The main outcomes achieved within phase one of the project were:

- A booklet was designed to ask the patient and their family and/or carers to provide information about the patient. This aimed to help hospice staff care for them in a way that promotes autonomy and dignity and alleviates distress.
- Resources were made available to support communication and help nursing staff provide appropriate occupation, relaxation and reminiscence activities which would give patients meaning and validation.
- Staff had greater understanding of the experiences of patients with cognitive impairment after a study day workshop for hospice staff on ‘The experience of cognitive impairment’.
- There was more participation, active learning and action planning as a result of a claims, concerns and issue exercise used with key stakeholders.

After eighteen months the project remains in the process of development and will continue beyond the scope of this report with elements of phase two being introduced.
Background
St. Gemma’s Hospice provides an integrated palliative care service comprising an in-patient unit with 32 beds, a day unit and community team. Patients with a life limiting illness are referred to the service for the purpose of symptom management, psychological support and/or end-of-life care. In line with the original vision put forward by Dame Cicely Saunders, founder of the modern hospice movement, St. Gemma’s Hospice looks to integrate research and education with clinical practice. This is done through a dedicated Academic Unit of Palliative Care which has affiliations with the local university. It supports research, education and training internationally, nationally and locally and aims to offer a structured and supportive learning environment for its staff.

Studies show that approximately 34-45% of patients experience some degree of cognitive impairment at the time of admission to palliative care units, which increases to 83% before death (Radbruch et al., 2000). Disorders that affect cognition include neurodegenerative, vascular, traumatic, toxic, anoxic and infectious processes resulting in neurocognitive deficits such as dementia and delirium (Buffum et al., 2007). Symptom management is a founding component of palliative care and relies on accurate assessment, which in turn relies on the ability of patients to communicate how they feel. Cognitive impairment can affect a person’s ability to report, describe and interpret their symptoms as well as understand the assessment questions and recall previous experiences of their symptoms (Wilson et al., 2006).

People experience different degrees of cognitive impairment. Some people with a milder form may be able to verbally report their symptoms but have difficulty giving comprehensive and detailed descriptions of how they feel. They may benefit from supportive and augmentative communication techniques. Exploring these practical approaches is advocated by the Mental Capacity Act (Department of Health, 2005). When a person experiences severe cognitive impairment, a person’s verbal communication skills diminish and a greater reliance is placed on observations of their behaviour. The majority of research in this field has looked at pain assessment in people with severe dementia and the development of behavioural pain assessment tools. Regnard et al. (2007) point out that as there is no current evidence of a specific sign or behaviour which distinguishes pain from other causes of distress in people with severe communication difficulties, these tools are in fact detecting the presence of distress. Once distress is detected, it is a matter determining the cause, which may be physical, psychosocial or emotional. Studies suggest that effective symptom assessment depends on an intimate knowledge of the individual with cognitive impairment (Cohen-Mansfield and Creedon, 2002; Falls et al., 2004). Understanding their normal state, including their routines, habits and needs, allows changes in behaviour to be identified and understood in context. This makes it easier to differentiate, for example, between pain, hunger, fatigue, and anxiety. Assessment should therefore include insights from carers familiar with the patient (Royal College of Physicians et al., 2007; Hadjistavropoulos et al., 2010).

Studies have shown that a lack of knowledge or confidence in responding to people who are distressed and suffering from a cognitive impairment is also a source of stress for professional carers (Beck, et al., 1999; Davison et al., 2007). This is supported by a previous study carried out by the project lead where hospice staff highlighted their concerns around communicating, assessing symptoms and understanding distress in patients with cognitive impairment (Chatterjee, 2012). Buffum et al. (2007) and Hadjistavropoulos et al. (2008) suggest it is reasonable that assessment methods and tools advocated for people with dementia be used for people with other causes of cognitive impairment. Working on this basis, the project lead, through a literature review, identified methods and tools that would support staff (Chatterjee, 2012). These include:

- Supportive and augmentative communication techniques - using words, pictures and gestures to enhance communication
- The ‘This is Me’ leaflet (Alzheimer’s Society, 2009) - working with the patient, family, carers to understand the likes, dislikes, habits, routines, life story and behavioural characteristics of the patient
- Disability Distress Assessment Tool (DisDAT) (Regnard et al., 2007) - a behavioural assessment tool that identifies distress
- Resources to stimulate activity, relaxation and reminiscence

It was felt that patients with dysphasia or extreme frailty and fatigue would also benefit from these methods as they too are likely to have difficulty with concentration and communication. The use of such methods and tools can promote autonomy, dignity and validate a person's life. It was this understanding that extended the scope of the project so that it encompassed providing a person-centered approach to symptom assessment and care delivery for a significant number of hospice patients who have or may in the future develop difficulty expressing their needs.

The aim of this project was to implement and embed the use of these methods and tools in practice using a practice development approach. Practice development methodology offers systematic processes to bring about the cultural changes that are required to firmly embed person-centred and evidenced-based care in practice. It acknowledges the importance of the ‘human factors’ such as staff wellbeing, support and learning, delivered through effective leadership and facilitation. It uses an active learning approach where creative thinking develops new understanding and learning that is transferred to the workplace. It integrates inclusive, participative and collaborative evaluation to establish and develop practice through a continuous process (McCormack et al., 2013a; 2013b; Dewing, 2009).

The project was in two phases. The first phase looked to improve the general skills of hospice staff in understanding and caring for patients who have difficulty communicating their needs. This was facilitated by developing an adapted form of the ‘This is Me’ leaflet (Alzheimer’s Society, 2009) and engaging with all staff involved in patient care on understanding and supporting people with cognitive impairment. In addition, various resources were made available to support nursing staff in providing patients with activity and occupation, comfort, reminiscence and relaxation.

In the second phase it is planned that a dedicated group of staff will increase their knowledge on using augmentative communication techniques and the DisDAT tool. It is anticipated that patients who experience persistent pain, discomfort and/or unresolved distress will be referred to this group to further enhance the assessment of their pain and distress and inform care plans.

This report will focus on phase one of the project as it is important initially to ensure that all staff have the skills to care for patients in ways that minimise general causes of distress. Then patients experiencing more complex symptoms will be identified and can then be assessed in a more structured way using the approaches outlined in phase two above. To support the project an application was made to the Patients First Programme at the Foundation of Nursing Studies (FoNS) supported by the Burdett Trust for Nursing, which provided individualised workplace support, workshop days for the project team and a small bursary.

Aim and objectives
Aims of the project (phase 1)
- To improve the skills of healthcare professionals in caring for palliative care patients who have difficulty expressing their needs
- To provide resources and tools to aid communication, symptom assessment and promote personhood
Objectives (phase one)

- To engage with key stakeholders
- To develop an adapted form of the ‘This is Me’ leaflet to meet the needs of hospice patients
- To develop and deliver a workshop to hospice staff involved in patient care on ‘Understanding cognitive impairment’
- To implement the use of the adapted form of the ‘This is Me’ leaflet along with resources to aid communication, occupation, relaxation and reminiscence
- To evaluate phase one of the project

A summary of methods and approaches

A project leader acts as a role model and works to generate interest and support among colleagues (Moran and Avergun, 1997). Facilitation skills are essential for effective leadership focusing on developing enabling relationships with participative and collaborative working within an organisation (Manley et al., 2013). Indeed, Cameron and Green (2009) suggest that teamwork is paramount to the delivery of practice development because of the level of work, energy and commitment needed to bring about change. Moran and Avergun (1997) identify the project team as the internal change drivers who will have the most impact on practice at the patient/client interface, while Roberts et al. (2008) highlight the importance of working through a multidisciplinary team to effect change throughout an organisation.

At St Gemma’s Hospice, the project team was an already established multidisciplinary group of healthcare professionals with a special interest in meeting the needs of hospice patients with dementia, learning disabilities and mental health concerns. It comprised a lecturer in palliative care and project lead (n=1), nurses (n=6), healthcare assistants (n=6), a social worker (n=1), an occupational therapist (n=1) and a complimentary therapist (n=1).

Table 1: A summary of the methods and approaches used in the project

| Raising Awareness | External drivers - national policies  
|                   | St. Gemma’s Hospice Quality Account  
|                   | Stakeholder meetings  
|                   | Project team meetings - claims, concerns and issues exercise  
| Adapting the ‘This is Me’ leaflet - adapted form named the ‘Helping Us Understand You’ booklet | Project team - questionnaire  
|                   | Drafts to clinical groups  
|                   | Patient and carer interviews  
| Using the ‘Helping Us Understand You’ booklet and resources to support communication, activity and occupation, reminiscence and comfort between staff and patients | Study day workshops  
|                   | Values and beliefs exercise  
|                   | Claims, concerns and issues exercise  
|                   | Clinical update training sessions  
|                   | Patient and carer views  
|                   | Leaflets, flyers, posters, bulletins  
| Project evaluation | Post workshop evaluations at the end of the workshop and after 9 months  
|                   | Claims, concerns and issues exercise with key stakeholder groups  

<table>
<thead>
<tr>
<th>Project activity</th>
<th>Dates</th>
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<tbody>
<tr>
<td>Project title and outline as entered on the FoNS website circulated to senior nurses, heads of departments, consultants and project team</td>
<td>Nov 2013</td>
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<tr>
<td>Project team meeting:</td>
<td>Jan 2014</td>
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<tr>
<td>• project action plan</td>
<td></td>
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<td>• claims, concerns and issues exercise around the implementation of the project</td>
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<td>• resources listed to be acquired</td>
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<tr>
<td>Questionnaire to the project team members on the 'This is Me' leaflet</td>
<td>Feb 2014</td>
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<tr>
<td>First draft of 'Helping Us Understand You' booklet circulated to senior nurses and the project team for comment</td>
<td>March 2014</td>
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<tr>
<td>Project team meeting - discussion</td>
<td>March 2014</td>
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<tr>
<td>Interviews with patients and carers about their thoughts on using the 'Helping Us Understand You' booklet</td>
<td>March/April 2014</td>
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<tr>
<td>Project entered into the St. Gemma’s Hospice Quality Account 2013-2014 as a priority for improvement under heading ‘the patient experience’</td>
<td>April 2014</td>
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<tr>
<td>Final version 'Helping Us Understand You' booklet agreed and approved by the senior hospice managers</td>
<td>May 2014</td>
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<tr>
<td>Preparation for study day workshops on 'The Experience of Cognitive Impairment’</td>
<td>May 2014</td>
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<td>• room booking</td>
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<td>• promotion</td>
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<td>• meeting with the project team to participate in workshop delivery</td>
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<tr>
<td>Study Day Workshops 1</td>
<td>June 2014</td>
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<tr>
<td>'The Experience of Cognitive Impairment' for healthcare assistants</td>
<td></td>
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<tr>
<td>Study Day Workshops 2</td>
<td>July 2014</td>
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<tr>
<td>'The Experience of Cognitive Impairment' for all clinical staff</td>
<td></td>
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<tr>
<td>Launch of the resources for use in the hospice - Hospice Bulletin, posters and display</td>
<td>August 2014</td>
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<tr>
<td>Meeting with senior nurses to discuss questions arising from the claims, concerns and issues exercise carried out by the Study Day Workshop participants around implementing the use of the 'Helping Us Understand You' booklet</td>
<td>August 2014</td>
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<tr>
<td>Meeting with project team</td>
<td>August 2014</td>
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<tr>
<td>• discuss questions arising from the claims, concerns and issues exercise carried out by Study Day Workshop participants</td>
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<tr>
<td>• project action planning</td>
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<tr>
<td>Launch of the 'Helping Us Understand You' booklet Posters, hospice bulletin and staff information leaflet</td>
<td>Oct 2014</td>
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<tr>
<td>Nine month post – Study Day Workshops evaluations</td>
<td>April 2015</td>
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<tr>
<td>Claims, concerns and issues exercise - senior clinical staff and project team members to evaluate the project and discuss the future direction</td>
<td>April 2015</td>
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Methods - Rationale

Questionnaire

A questionnaire is a method of collecting data from individuals. This method was used as it was important to gain the perspectives of the whole group but it was difficult for everyone to attend a meeting at this time. Open questions were used to allow participants to express their opinions and ideas (Murphy-Black, 2000). The questionnaire was sent to members of the project team to gain their insight into the current use of the ‘This is Me’ leaflet (see Appendix 1) in practice and to consider how this could be improved on.

Values and beliefs clarification exercise

A values and beliefs clarification exercise is a practice development tool for developing a common shared vision and purpose. It can be the starting point for cultural change in the workplace. Identifying a common shared vision then recognising the gaps between this and what actually happens in practice can help identify and overcome the barriers that exist to practice change. These barriers may present within individuals, teams or organisations (Royal College of Nursing, 2007). A values and beliefs clarification exercise was undertaken by participants at the start of the ‘Experience of Cognitive Impairment’ study day workshops to gain a consensus on the understanding of person-centred care, how it is best achieved and raising awareness of the barriers that exist to delivering it.

Claims, concerns and issues exercise

The claims, concern and issues (CCI) exercise (McCormack et al., 2013b, derived from Fourth Generation Evaluation (Guba and Lincoln, 1989)) is designed to gain the views and perspectives of stakeholder groups involved with a project.

- Claims - individuals are asked to identify favourable assertions about a project and its implementation
- Concerns - individuals are asked to identify unfavourable assertions about a project and its implementation
- Issues - questions that any reasonable person might ask about a project and its implementation. These usually arise out of the concerns.

This exercise can be used repeatedly with various groups to highlight improvements achieved through a project, what difficulties remain and to develop an action plan to overcome the difficulties. It can also be used throughout a project to enable a cyclical process of action planning and evaluation.

CCI exercises were completed on a number of occasions. One was undertaken with the project team initially (see below) and an action plan for the project was developed. One was also completed by the participants of study day workshops and used to develop guidelines for implementing the ‘Helping Us Understand You’ booklet into practice. Lastly, one was undertaken by members of the project team and senior clinical staff at the end of the project period to evaluate the work of the project to date and to develop a plan to address areas identified for improvement.

Interviews

Interviews are a useful way of finding out about a person’s perception or opinion on a specific matter. An unstructured interview is seen as a dynamic interaction between two people which takes place in a particular set of circumstances for a particular purpose (Pontin, 2000). The importance of gaining and acting on feedback from service users to develop services and care practices has been highlighted since development of the National Service Frameworks, long-term strategies for improving specific areas of care (Department of Health, 2000). This is an action area further endorsed by the policy document Compassion in Practice (Department of Health, 2012a).
Unstructured interviews were carried out with hospice patients and carers to gain their views and opinions on the format and use of the 'Helping Us Understand You' booklet.

**Approaches in practice**

**Raising awareness**

Organisations need to respond to external change drivers such as health and social care policy (Moran and Avergun, 1997). Following the Francis report (Francis, 2013) into failings at Mid Staffordshire NHS Foundation Trust, developing person-centred approaches to care has been high on the health and social care agenda. With an ageing population in the UK and the incidence of dementia on the increase, the Prime Minister set out a dementia challenge (Department of Health, 2013) which includes developing communities in which health and social care services are fit for purpose to work with people with dementia. Help the Hospices (Hospice UK, 2015) stress the importance of hospices becoming strategic partners in delivering care to this population.

Given these developments, a project that looks at supporting the needs of hospice patients with cognitive impairment or extreme frailty was supported by the hospice management. The profile of the project was raised further when following meetings with senior clinicians, it was identified as a quality priority for the patient experience category and entered into the Hospice Quality Account Report 2013/14. A Quality Account is an annual requirement set out by the Health and Social Care Act (Department of Health, 2012b). It measures the quality of services of NHS healthcare providers, including the independent sector, based on quality indicators for patient safety, the effectiveness of treatments that patients receive and patient feedback about the care provided. This meant it was necessary to set out how the improvements would be achieved over the following year (the project objectives) and review the progress at the end of the year.

**Project team - claims, concerns and issues exercise**

The initial aim of the project was to improve the assessment of pain and distress for hospice patients with cognitive impairment using the methods and tools identified in the literature. However, during the first two Foundation of Nursing Studies (FoNS) study days attended by four members of the project team, it became apparent that these methods and tools could have wider benefits. They could promote a person-centred approach to care that would benefit a significant number of hospice patients including those with dysphasia or extreme frailty who are likely to experience difficulty expressing their needs as well as those with cognitive impairment. This rationale was accepted by the whole project team and through further discussion it was identified that the 'This is Me' leaflet (Alzheimer's Society, 2009) designed to support the care of people with dementia and currently promoted for use in the hospice should be adapted to allow a more generic use.

At this initial point in the project a claims, concerns and issues exercise was carried out with the project team in order to gain their thoughts and ideas about the project and to develop an action plan.
Table 3: Results of the initial project team ‘claims, concerns and issues’ exercise Jan 2014 (n=15)

Claims: positive assertions about the project
The team felt that the project would help them engage with different staff groups to disseminate their understanding of the tools and methods to support hospice patients with difficulties communicating their needs in a more planned and structured way. They felt that having the support of the FoNS team for a project that ‘belonged’ to the hospice would motivate staff as ‘anything that can help improve our own patient care is good’. They saw it as a good opportunity ‘to reflect on practice’, ‘share and discuss ideas, views and difficulties’ and to ‘move forward’, ‘act in patients’ best interests’ and ‘implement new ideas’. It was also felt that the project would ‘empower staff, patients and families’. One person reported that they were enjoying being part of the project team.

Concerns: negative assertions about the project
The main concerns were around having enough time, resources and appropriate channels of communication to achieve effective implementation of the project. It was acknowledged that ‘application may be difficult and lengthy’ and that there may be a degree of resistance to overcome ‘not everyone may feel that this work benefits patient care and may feel it is a burden to their work load’. It was felt important that the group had recognition and its purpose was understood by staff beyond the group itself. To achieve this it was identified that time and resources for engaging and training hospice staff across all disciplines was needed. The issues arising from the concerns were transformed into questions that the project team could work with to produce an action plan.

Questions arising from CCI exercise
• How do we disseminate the work, information and understanding of the project to all staff members?
• How do we ensure resources developed or advocated by the project team are used appropriately with maximum effectiveness?
• How do we ensure that the project team get enough protected time to meet regularly as a group?
• How do we ensure that the hospice leadership team value the work of the project team so it can continue to get support and funding?
• How will this project be evaluated?

Action plan
1. The project lead to set monthly meeting dates in advance and to contact and meet individually those who cannot attend meetings.
2. To complete CCI exercise following each meeting and review the action plan.
3. To organise study day workshops on ‘The experience of cognitive impairment’ for all members of hospice clinical teams.
4. To launch the use of the booklet ‘Helping Us Understand You’ at these events.
5. To keep a high profile by attending ward/team meetings for different groups of staff, reporting significant developments in the hospice bulletin.
6. To work within the hospice systems for quality improvement initiatives.

Although the project lead set dates in advance for monthly project team meetings, these were not achieved due to the difficulties with staffing levels at a time when the service was undergoing a restructure. The project lead made contact with individual members or small groups as often as possible and tried to keep everyone informed of progress by email or written information. This
method of communication however was ad hoc and appeared to slow the progress of the project. It also felt less inclusive as it was difficult for the project lead to engage with all members equally. Monthly meeting of the project group would have allowed greater sharing of ideas and goals, more rigorous action planning and maximised involvement of the whole project team.

During the first period of the project when the hospice was going through the restructuring process there were changes to clinical teams and it could be suggested that staff appeared to be less motivated to engage with the project as they were having to cope other changes as well. It also meant there were changes to established lines of communication and new ones were being developed.

**Development of the 'Helping Us Understand You' booklet adapted from the 'This is Me' leaflet**

The project team had previously been responsible for the initiative to implement the use of the 'This is Me' leaflet into practice in the hospice. The idea was that it would be appropriate for anyone with cognitive impairment not just those with a diagnosis of dementia. The project lead developed a questionnaire for the project team to complete to find out about their views and experience of using this tool and to consider possible future developments. Open questions were employed to encourage original thoughts and opinions.

**Table 4: Results from the questionnaire (n=15)**

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<thead>
<tr>
<th>Question 1 - What information do we hope to gain by using it?</th>
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<tr>
<td>The project team listed a range of information that they hope to gain from patients and families completing the 'This is Me' leaflet suggesting that it could be 'personal information about the patient's likes, dislikes and idiosyncrasies' or 'just the little things that make them comfortable'. They suggest that gaining information on a person's life story, interests, hobbies, occupations, habits, family dynamics, significant figures and experience of loss can help build up a picture of that person and contribute to developing relationships of trust with patients and their families.</td>
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<th>Question 2 - How does the information gained help us care for patients?</th>
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<td>It was noted that when patients have difficulty communicating for any reason, having 'as many clues as possible' can 'help avoid the frustrations caused by the patient attempting to communicate their wishes'. It was also suggested that this understanding can help staff with 'rapport building', 'give more tailored individualised care' and 'plan activities specifically for the needs of patient and carers'.</td>
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<th>Question 3 - What are the barriers to using it?</th>
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<td>The project team were able to identify a number of barriers which would indicate that they were reflecting on experience. They suggested that when a person lacks capacity it is necessary to 'rely on the carer's perception of the patient and this may be difficult if they have not had a close relationship with the patient'. Other limitations could be that the carer as well as the patient may have language difficulties or 'just misunderstand how important 'little things' can be'. They suggested that getting families to acknowledge its value is often difficult and relevant information is often omitted. Time for families and carers to complete the leaflet and for staff to support them was also cited as a barrier. It was also acknowledged that staff need time to read the completed leaflet and share the information with the multidisciplinary team.</td>
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<th>Question 4 - How can we improve practice?</th>
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<td>It was suggested that study sessions should be held to increase staff understanding so 'all staff are familiar with the use of the leaflet and its aims'. It was suggested that the project team could act as champions 'passing information on'. It was felt that it offered a person-centred approach that could be of value to all hospice patients not just those with dementia/cognitive impairment and therefore</td>
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Designing the ‘Helping Us Understand You’ booklet

Taking the points raised in the questionnaire (above), the ‘Helping Us Understand You’ booklet was designed by the project lead in consultation with the project team so that it would be suitable for patients coming into contact with hospice services (see Appendix 2). The front sheet gave information to the patient and carer on the rational for its use, highlighting how the information would be used by staff to provide individualised care and to anticipate a person’s needs (see Appendices 3 and 4). Reassurance was given to patients and their families that they owned the information and could choose what they wish to share. The back page has a place for the patient or their advocate to sign to say they are happy to share the information with members of the MDT involved in their care.

The headings under which the information is asked for are broad and aim to capture subtle and detailed information about a person and their life that would not normally be identified during the hospice admission process. The headings are as follows:

- My name is
- I like to be known as
- People, pets, places and things that are important to me
- My normal routines and habits
- My likes and dislikes
- Things that cause me to become anxious and distressed
- How might you know when I am anxious or distressed
- Things that help me feel better and help me to relax
- Other things to know about me
- My life story

These were circulated to the project team who were asked to identify prompts that could be listed under each of the headings to give the patient and their family examples of the type of information that would be useful in providing care for them. For example a suggested prompt for the heading ‘People, pets, places and things that are important to me’ is ‘who might you want to speak to if you are feeling upset’. Patients coming into the hospice in-patient unit are likely to be experiencing deteriorating health, raising the question why it is important to understand their normal routines if they are no longer physically able to maintain them. So, under this heading there is the explanation that knowing about a person’s normal routines ‘will help us get a sense of how you may be feeling at particular times’. It was also noted that people tend to have current photographs of their family with them. Under ‘My life story’ they are encouraged to have pictures from their past with them to help build the picture of their life.

A draft of the booklet was sent to the senior members of the clinical teams for comment and minor changes were suggested with terminology for example replacing ‘nausea’ with ‘feeling sick’ to make it more appropriate for the lay person. A graphic design artist was approached to design images to use in the booklet. The images were designed based on the words; person-centered, support,
comfort, individual and life story. The final version of the booklet was approved for use in the hospice by the clinical effectiveness group and the patient information group.

**Interviews with patients and carers about the 'Helping Us Understand You' booklet**

Patients who were able to adequately express their needs and had good insight into their illness were approached to comment on the booklet design and use. They were given a letter to introduce the project and to reassure them that confidentiality would be maintained (see Appendix 4) to ensure that they were giving informed consent to contribute to the project. Two patients completed the booklets for themselves and reported that it was a useful exercise and while they could currently express their needs clearly they understood its value for when they became less well: ‘it would help in understanding the whole person, it’s that spiritual element that’s so important at this time’. They both reported that the prompts were very helpful and one of the patients particularly noted that ‘he would not have given the same amount of detail without being guided by the examples’. One of the patients reported that if she had needed support to complete the booklet it would preferably be from her best friend who knew her better than her family. The wife of one of the patients reported that if her husband had been unable to complete it for himself she would have found the situation difficult: ‘if somebody gave it to me I would be horrified, I don’t like filling in forms. In our marriage it has always been my husband that has done that part. He is an engineer so he is good at it’. She felt it would be an extra burden for her at a time when she was already stressed but conceded that she would cope better if someone talked through it with her and wrote down her responses for her. These insights highlight the importance of talking through the booklet with the patient and their family/carers to determine the best approach to gaining the information.

**Study day workshops on 'The experience of cognitive impairment'**

The purpose of engaging hospice staff about the difficulties experienced by people with cognitive impairment was to help them to understand the importance of knowing as much as they can about the person and how this information can be used to support them to deliver person-centred care. The study day workshops were based on the principles of adult learning. Kolb (1984) sees learning as knowledge created through the transformation of experience. He argues that while individuals have different personal learning styles, engaging with a variety is needed for effective learning. His cycle of experiential learning comprises learning from: concrete experience, reflective observation, abstract conceptualization and active experimentation. The study day workshops aimed to incorporate these by adopting different teaching approaches through a mix of audio and video materials, information sharing, participatory exercises and reflecting on practice.

In brief, the study day workshops timetable was as follows:

- Introduction, values and beliefs clarification exercise, PowerPoint presentation
- Workshop 1 - supporting a patient with cognitive impairment: a case study
- Lunch, displays and activities
- Workshop 2 - memory and behaviour
- Workshop 3 - person-centred care: what does it mean for someone who has lost their decision-making capacity?
- Claims, concerns and issues exercise
- Concluding activities
- Evaluations

See Appendix 5 for the workshop programme.

Members of the project team were involved in the delivery of the sessions. This helped them to engage with the project and allowed other staff members to identify them as champions of the initiative. Two workshops were held with the following staff members attending:
• Study Day Workshop 1 (SD1) = healthcare assistants (HCAs) x 6
• Study Day Workshop 2 (SD2) = research nurse x 1, complimentary therapist x 1, physiotherapist x 1, therapy manager x 1, community nurse specialist x 1, ward sisters x 2, registered nurses (RNs) x 5, HCA x 1 (total = 13)

Table 5: The workshop aims and learning outcomes

<table>
<thead>
<tr>
<th>Workshop aims</th>
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</tr>
</thead>
<tbody>
<tr>
<td>• To explore our values and beliefs about person-centred care and develop a</td>
<td>• To explore how the skills developed in dementia care practice</td>
</tr>
<tr>
<td>shared vision to inform the way we care for people with cognitive impairment</td>
<td>can be used to support the needs of palliative care patients</td>
</tr>
<tr>
<td>• To explore how the skills developed in dementia care practice can be used</td>
<td>with cognitive impairment</td>
</tr>
<tr>
<td>to support the needs of palliative care patients with cognitive impairment</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Learning Outcomes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• To understand the term cognitive impairment and consider the incidence of</td>
<td>• To understand the common difficulties experienced by people</td>
</tr>
<tr>
<td>cognitive impairment in palliative care patients</td>
<td>with cognitive impairment and recognise ways they can be</td>
</tr>
<tr>
<td>• To understand how the brain works and how damage to different areas of</td>
<td>supported to improve symptom management, quality of life and</td>
</tr>
<tr>
<td>the brain affects a person's function and behaviour</td>
<td>end-of-life care</td>
</tr>
<tr>
<td>• To understand the common difficulties experienced by people with</td>
<td></td>
</tr>
<tr>
<td>cognitive impairment and recognise ways they can be supported to</td>
<td></td>
</tr>
<tr>
<td>improve symptom management, quality of life and end-of-life care</td>
<td></td>
</tr>
</tbody>
</table>

Values and beliefs clarification exercise

Person-centred care should be embedded in any healthcare practice and is particularly important in palliative care especially when caring for the most vulnerable patients with cognitive impairment. Person-centred care is a broad term and may mean different things to different people. The first exercise of the workshop aimed to explore the participants’ values and beliefs about person-centred care in order to develop a shared understanding to influence the delivery of care throughout the hospice services.

The participants were invited to write individual statements on sticky notes for the headings:

- I believe the ultimate purpose of person-centred care is:
- I believe this purpose can be achieved by:
- I believe the factors that help us achieve this purpose are:
- I believe the factors that hinder us from achieving this purpose are:
- Other values and beliefs I consider important in relation to person-centred care are:

One sheet of flip chart paper was used for each of the first four headings and participants were asked to place their statements under the appropriate heading. Then a group of participants was assigned to each sheet. They were asked to read through all the statements, categorise them into themes and come up with a shared statement for the group reflecting all the contributions.
Table 6: Themes arising from the values and beliefs clarification exercise

<table>
<thead>
<tr>
<th>We believe the ultimate purpose of palliative care is:</th>
</tr>
</thead>
<tbody>
<tr>
<td>SD1 - Individuality, understanding</td>
</tr>
<tr>
<td>SD2 - Care that meets the needs of the individual and understanding the person</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>We believe this purpose can be achieved by:</th>
</tr>
</thead>
<tbody>
<tr>
<td>SD1- Communication, gaining information, observing, listening</td>
</tr>
<tr>
<td>SD2- Communication-talking, listening, use of aids</td>
</tr>
<tr>
<td>Understanding the patient’s needs - including through staff training</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>We believe the factors that hinder us from achieving this purpose are:</th>
</tr>
</thead>
<tbody>
<tr>
<td>SD1- Lack of knowledge, inexperience, judging, pre-conceived ideas, time, difficulties in communication, lack of continuity</td>
</tr>
<tr>
<td>SD2 – Time</td>
</tr>
<tr>
<td>Resources/funding</td>
</tr>
<tr>
<td>Knowledge/poor communication</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>We believe factors that help us achieve this purpose are:</th>
</tr>
</thead>
<tbody>
<tr>
<td>SD1- Listening, talking, understanding the patient/person, knowledge</td>
</tr>
<tr>
<td>SD2 - Educating a multi-disciplinary team to work holistically towards patients goals</td>
</tr>
<tr>
<td>Excellent communication skills in order to listen and understand the needs of patients and their carers/families</td>
</tr>
<tr>
<td>Resources</td>
</tr>
</tbody>
</table>

The values of the participants from both workshops were similar and shared those of the project. Participants identified training, communication skills, resources and a multidisciplinary approach as the way to support the delivery person-centred care for hospice patients. Lack of time was identified by both groups as a hindrance to delivering person-centred care. This opened up a discussion around the question whether more time spent initially in getting to know a patient would be likely to save time in the long run by making it is easier to anticipate their needs and avoid or alleviate their distress.

**Introductory PowerPoint presentation**

The project lead introduced participants to the project and talked about its value for hospice patients using a PowerPoint presentation. The presentation aimed to get the participants thinking about what cognitive impairment is and the extent it affects palliative care patients. During the presentation the participants were asked to consider how cognitive impairment affects people, discussing key issues such as communication, spirituality, memory loss and psychosocial needs.

**Workshop 1 - supporting a patient with cognitive impairment: a case study**

This workshop was organised and delivered by two members of the project team; an occupational therapist and a complimentary therapist. They developed a fictional case history of a gentleman with cancer and dementia who was being supported by the hospice to be cared for at home. They had completed a ‘Helping Us Understand You’ booklet for him. Based on this information they asked...
participants to consider how his home environment could be adapted to support him and what advice could be given to his wife to help him achieve a quality of life through appropriate activity, occupation and relaxation techniques.

**Workshop 2 - memory and behaviour**

This workshop was delivered by an external speaker who was the lead for mental health nursing at the local university. Participants watched the film ‘Barbra’s Story’ about a widow with dementia and cancer and her experience of NHS services both in hospital and at home (see https://www.youtube.com/watch?v=DtA2sMAjU_Y). It is designed to raise staff awareness of how it feels to be a patient with dementia. The participants were asked to reflect on the film to help them consider their own interactions with such patients.

The session focused on the common types of behaviour exhibited by people with dementia and looked at ways of responding to this behaviour. It also highlighted the importance of understanding a person’s behaviour as their way of expressing an unmet need when they are unable to articulate this need.

**Workshop 3 - person-centred care: what does it mean for someone who has lost their decision-making capacity?**

This workshop was delivered by the project lead and a member of the project team who was a social worker. The participants were asked to engage in an exercise to consider their own personhood. They are given a page with four interlocking circles printed on it and were asked to complete the following:

- Circle 1 - write what you consider to be your role in life
- Circle 2 - write down your strengths
- Circle 3 - write down your weaknesses
- Circle 4 - write down who or what is important to you

They were then asked to cut around circle 3 and throw the others bits into the bin. They were asked to consider how they would feel if all future communications with them highlighted this weakness. This exercise asks participants to reflect on the fact that people with cognitive impairment are more likely to have their weaknesses rather than their strengths emphasised, which undermines personhood (Sheard, 2003, pp 46-47).

The participants were given a case study about a hospice patient with dementia who lacked capacity to make a decision about his place of care. He continually asked to go home but through best interest decision-making with the hospice team and his family he was discharged to a care home. Participants were asked to reflect on what could be done to maintain the personhood of this patient who lacked autonomy (see Appendix 6). They were also asked to reflect on their practice and times when they felt they had supported patients to maintain their personhood. They gave the following examples:

- A gentleman who had a brain tumour and was cared for in the hospice used to call out his granddaughter’s name. Staff asked the family about this and they said that because the granddaughter had been at home with him while studying for her exams he would call her when he needed help to get to the bathroom. Staff then understood that when he called for his granddaughter he usually needed to go to the toilet.
- A gentleman with a brain tumour who was being cared for in the hospice had been a local bus driver. He was very happy when staff asked him about his bus route and he would name all the stops.
- A lady with dementia who was being cared for in the hospice used to work in a department store. It was noticed that when she took off her cardigan she would fold it in a special way
with the arms tucked in. Staff helped her to feel occupied by asking her to fold and sort some laundry.

This exercise helped participants acknowledge that they already have many skills in supporting people with cognitive impairment.

Claims, concerns and issues exercise
Finally the participants were given a ‘Helping Us Understand You’ booklet and asked to complete it for themselves. This was to help them engage with the booklet and think about the type of information that would support them if they needed to be cared for. After that, a claims, concerns and issues exercise was undertaken in relation to the new booklet, and the finding are displayed in table 7 below.

Table 7: Claims, concerns and issues exercise carried out by the study day workshop participants (SD1 n=6, SD2 n= 13)

<table>
<thead>
<tr>
<th>Claims</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>It was felt by one participant that the booklet was 'more appropriate and informative for all, than the 'This is Me’ leaflet' with several responses suggesting that it could be used with all hospice patients and ideally it 'can be started in the community/day hospice and follow patients through on their journey' this could 'allow continuity of care across the service if used by all'. Its value was recognised as supporting individualised, person-centred care and that it 'helps communication and helps to avoid frustration'. Other benefits to using it suggested were that it could be 'helpful for staff when making decisions', 'used as part of the MDT discussions', 'prompt other conversations about dying' and 'lead to advance care planning'. Another positive attribute identified is that 'patients can choose if they want to fill it in and what they want to share with us'.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Concerns</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A variety of concerns about how the booklet could be effectively implemented into practice were listed by the participants these included:</td>
<td></td>
</tr>
<tr>
<td>'Resistance from some members of staff'</td>
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<tr>
<td>'Time to use it'</td>
<td></td>
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<tr>
<td>'Patients unwilling to discuss information'</td>
<td></td>
</tr>
<tr>
<td>'People not reading and understanding the information'</td>
<td></td>
</tr>
<tr>
<td>'Something new – hard when we have had so many recent changes'</td>
<td></td>
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<tr>
<td>'If the patient is unable to fill it out does the family/next of kin know about their routines etc?'</td>
<td></td>
</tr>
<tr>
<td>'Knowing how to approach the person to ask them to fill it out'</td>
<td></td>
</tr>
<tr>
<td>'Some people may have reading and writing problems'</td>
<td></td>
</tr>
<tr>
<td>'Maintaining it - if it follows the patient through the different services will it still be intact/legible?'</td>
<td></td>
</tr>
<tr>
<td>'Where to keep the?. Could they be kept in the coloured folders in patients’ rooms and would they need to be brought out for MDT and ward rounds?'</td>
<td></td>
</tr>
<tr>
<td>'How do we manage different opinions between family members/conflicting ideas?'</td>
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</tbody>
</table>

| Issues arising from these concerns were converted to questions that would need to be addressed to support the effective implementation of the 'Helping Us Understand You' booklet into practice. These questions were discussed with the participants of the study day workshops, project team and sent to the heads of the clinical teams. The responses were collated and along with the information from the patient and carer interviews a leaflet was prepared to be given to staff to help them with the implementation (see Appendix 7). |
Displays and activities during the lunch time period

In one room the project team displayed posters on:

- Words and pictures
- Supportive communication tips
- Visual perceptual difficulties
- Rummage and reminisce (see Appendices 8A – 8D)

A couple of case studies were displayed on understanding behaviour (see Appendices 9A and B).

Exercises were set up including:

- Drawing around a shape whilst looking in a mirror- this was to demonstrate the feeling of frustration and exhaustion when doing everyday tasks requiring much effort and concentration.
- Where’s Wally - participants were asked to find the figure in a crowded picture to demonstrate that with visual perceptual difficulties people may find it hard to identify and locate things in a crowded environment.
- An online exercise that leads the participant around a living room to show how an apparently normal environment can appear treacherous to someone with visual perceptual difficulties. http://www.scie.org.uk/assets/elearning/dementia/dementia05/resource/flash/index.html

The resources purchased as part of the project were also displayed. During an extensive lunch period participants were invited to stroll around the room, read the information, participate in the activities and look at the resources. The project team were available to answer questions and discuss the use of the resources.

Concluding activities

The study day workshops were concluded with the participants watching a video clip of Naomi Feil, founder of Validation Therapy. It shows a breakthrough moment of communication with Gladys Wilson, a woman with advanced Alzheimer’s disease and virtually no verbal communication. Through Naomi’s touch, rhythm and song (spiritual church songs familiar to Gladys), Gladys opens her eyes, becomes animated and joins in with the songs. This demonstrates that through small acts it is possible to have an impact on a person’s quality of life. Naomi reports that you may not make the connection every time but when you do it is very special. https://www.youtube.com/watch?v=CrZXz10FcVM

The concluding thoughts for the day were:

- A person’s behaviour is their way of communicating
- Our job is to try to understand their behaviour
- IT IS NOT EASY
- It is like piecing together a jigsaw the more pieces of information we have about someone the better we are able to understand them
- The hospice is not a long term care setting and hospice patients often have rapidly changing healthcare needs
- We might not always get it right but we can try our best

In recognition of the job they do and as a memento of the study day, participants were given a stretchy stress relieving figure and a picture card with the phrase ‘I am doing the best I can whatever I am feeling’.
The study day was participative and interactive. It aimed to increase staff awareness of what it is like to experience cognitive impairment. It encouraged staff to recognise the difficulties patients may experience and to become creative in supporting them to maintain their personhood and individuality. The study days also aimed to raise awareness of the resources available and how they could be used. They were introduced to the ‘Helping Us Understand You’ booklet on several occasions during the day and given the opportunity to view all the resources. It further aimed to raise the profile of the project team so that staff would consider asking for their advice in the future.

Two study days were planned and aimed at all members of the multi-disciplinary team. The facilitator from the university was asked to contribute to raise the profile of the day and to bring in the perspective from a mental health background. One of these study days was cancelled because there were staff shortages on the wards due to sickness and difficulty recruiting trained nurses into vacant posts. During this period there was bed closure on the in-patient unit to keep the ratio of qualified nurses to patients at an adequate level. This meant there were more healthcare assistants rostered to work than required on the ward. The opportunity was therefore taken to hold one study day for healthcare assistants only. This healthcare assistant study day (SD1) was a small group and the participants knew each other well and readily contributed to discussions. The multidisciplinary study day (SD2) had more participants and they did not all know each other very well. It took more time for the participants to engage in discussions. On reflection, during the introductory PowerPoint presentation, it may have been better to get participants to form small groups to consider the questions posed rather than hoping to gain responses from the larger group. The healthcare assistants reflected well on their everyday care experiences and offered some very practical solutions and insight. The multidisciplinary participants expressed similar values and beliefs and understanding of the difficulties experienced in practice, they also offered more thoughts and ideas from a strategic point of view. There were several senior staff with leadership roles in clinical practice as well as those working predominantly in direct patient care. This is important for the dissemination of the knowledge into practice. Both study days gave valuable insights during the CCI exercises to support the implementation of the ‘Helping Us Understand You’ booklet.

End of day study day workshop participant evaluations [n=19]
The participants were given a list of adjectives and asked to circle the ones they felt appropriate. They were then asked to identify the most useful and the least useful aspects of the day along with any additional comments. The findings are summarised in the graph below.
It can be seen that a majority of participants for both the workshop days described the day as ‘thought provoking, valuable and interesting’. Participants also reported that they found it useful to understand the difficulties that people with cognitive impairment experience and ways they can support them. They recognised the importance of adapting the way they communicate and manage the environment.

‘Opening up my mind to how someone with cognitive impairment feels.’
‘The all-encompassing multi-faceted nature of dementia and some ways to meet the challenges.’
‘Understanding the visual and physical implications of dementia as well as problems with memory.’
‘Things that we can do to improve a patient’s life while we are caring for them.’
‘Information regarding changes that can be useful in the environment and communication.’
‘How I can be more aware of any communication with people with cognitive impairment.’

They reported that they found ‘Barbara Film’, ‘Video clips’ and exercises useful:
‘The front room with circle that changed patterns to flies and mat to a black hole.’
‘The videos were good and thought-provoking.’
‘Tasks that we did for ourselves, I found interesting to put yourself in the position of someone who is frustrated.’

They reported that it was good to be introduced to the resources available:
‘Now have more “tools” to use when dealing with cognitive impairment.’
‘What is available as I was not aware that we had a lot of it.’
Generally the participants appeared motivated by the day:
'I was feeling fed up but I am now inspired to do more.'
'Very helpful day that will help me in practice in this challenging field of care.'
'All very useful and now have more “tools” to use when dealing with cognitive impairment.'
'A well put together course providing lots of information enabling staff to improve care. Fantastic course!!'
'All clinical staff with patient contact should do this.'
'I look forward to having access to the resources and utilising them with patients.'

The engagement of the project group was commended:
'Lunchtime practical sessions with project group members – doing quiz/games etc was a good idea as they are so enthusiastic about their focus group (and involves them in information/practical teaching).'

One participant reported the value of time out of clinical practice to engage in reflection:
'It has been nice to have a day to think about these things without being rushed.'

While many had nothing to report as ‘least useful’, one participant felt ‘maybe lunch could be slightly shorter.’ This would suggest that this person did not engage fully with the lunchtime displays and activities. One participant reported ‘drawing around a shape - it worried me that I couldn’t do it!’ This suggests that the exercise was not adequately explained to them. One participant felt that ‘we all try and individualise care to a patient’s needs already.’ It may be that they felt that current practice was adequate and did not see the need of further resources.

**The launch of the ‘Helping Us Understand You’ booklet**
This took place on one day in October 2014. The booklets were made available for the in-patient unit, day services and community service. Simultaneously the leaflet on implementation into practice (see Appendix 10) was given out to staff and posters (see Appendix 11) were displayed for staff to highlight the value of ‘knowing the patients and families, explaining the initiative and referring them to the hospice staff for more information’. The posters were displayed on notice boards. The project team members’ names were displayed as champions for the initiative. All the information and publicity materials sported the image that was on the front of the ‘Helping Us Understand You’ booklet. The use of the imagery was to increase familiarity and raise its profile.

**Resources available to staff within the hospice**
The aim of the project was to promote person-centred care and in doing so alleviate and avoid unwarranted distress. Knowing the person can support staff to recognise and anticipate their needs. Patients admitted to the in-patient unit of the hospice are likely to be experiencing changing functional and cognitive abilities and changing needs. The project team felt it important for staff on the in-patient unit to have access to resources that were easy to implement. A list of resources was compiled and purchased through the hospice equipment budget. The resources included:

- Pictures to share books
- Pictures to share DVDs
- Memory bank books
- Toilet door signs
- Day/night/calendar clocks
- Fibre optic lamp
- Rainbow projected image
- CANGE cancer series accessible information books
• PictoComm - communicating with picture book
• Items to look and fiddle with in a 'rummage and reminiscence box'

Through the use of these resources staff could help a person to be orientated to time and to their environment. By providing activity and occupation that is achievable and meaningful they could support a person’s sense of value and self-worth and through reminiscence and sensory stimulation they could validate a person’s life and promote relaxation and comfort.

**Mandatory Clinical Update Sessions (3 sessions n=18 RNs)**
The project lead took the opportunity to deliver a session during the Mandatory Clinical Update training for nurses. During a 1.5 hour session staff were given an outline of the project, asked to complete a 'Helping Us Understand You' booklet for themselves and given the implementation leaflet to consider. They were also shown the video of ‘Barbra’s Story’ and engaged in a facilitated discussion following this.

**Evaluation of phase one of the project**
This phase of the project was evaluated in several ways:
• Participants of the study day workshop were asked to complete an evaluation nine months after attending it
• A record was kept of the number of 'Helping Us Understand You' booklets completed by patients and their families over a two month period following its implementation into clinical practice
• A claims, concerns and issues exercise was completed by senior nurses and the project team

**Evaluation post nine months of the workshop days**
These evaluations were used to identify whether after a nine month period, the participants had retained a level of understanding and implemented any of their knowledge into practice. Participants were asked to list three things they felt they had learnt from attending the study day workshop and give examples of how they had used the knowledge in practice. Nine out of 16 evaluations were returned (three members of the staff who attended the workshop had since left employment with the hospice).

The evaluations identified that the participants valued their greater understanding of the needs of people with cognitive impairment and recognised that 'cognitive impairment is not just about memory but behaviour and language as well' and that 'fatigue, anxiety and physical conditions' play a part. They gave examples of having a greater understanding of the importance of acknowledging a person’s emotions and feelings: 'emotional memories are used to make sense of the present'; 'patients may be asking for someone/something. Previously I would have put it down to their confusion but now I can see it could be due to fear, for example'. There was also understanding of the need to be 'more patient than usual due to frustrations that they may experience when trying to express their needs, emotions etc.' The importance of working with the family to get as much information about the person as possible was identified 'extra knowledge of history/background really helps to gain trust'. Several respondents reported greater awareness of the environment and the video clip of the living room was referred to, 'patterns on the wall paper, rug on the floor etc coming 'alive''; 'delusions are often made worse by environmental factors such as busy patterns'. Three respondents referred to people with dementia rather than using the more inclusive term of cognitive impairment. The majority highlighted that this greater understanding supported them to provide more person-centred, individualised care: 'I certainly approach patients with cognitive impairment with more empathy, patience and insight'. A few gave more specific examples of how they have used their understanding to improve their practice: 'I have used some of the resources successfully... the light box (projects an image of a rainbow) was used as a distraction for a patient...
with special needs and the picture books have been useful for people who require some occupation but lack concentration to read a book or watch TV; 'Given me the understanding of how to gently move on the conversation and assessment when we seem to be stuck'.

The number of 'Helping Us Understand You' booklets completed by patients and family members over a two month period

Table 8: Number of 'Helping Us Understand You' booklets completed

<table>
<thead>
<tr>
<th>Ward</th>
<th>Number of Booklets Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ward 1</td>
<td>4 (3 patients with cognitive impairment, one with dysphasia)</td>
</tr>
<tr>
<td>Ward 2</td>
<td>5 (patients with cognitive impairment)</td>
</tr>
<tr>
<td>Community</td>
<td>1 patient with cognitive impairment</td>
</tr>
<tr>
<td>Day Hospice</td>
<td>0</td>
</tr>
</tbody>
</table>

Claims, concerns and issues exercise completed by senior nurses and the project team

The CCI exercise was completed nine months after the workshops during the project team's latest meeting which included several senior nurses. The number of respondents was as follows: senior nurses [n= 3 out 4 responded] and project team [n= 8 out of 13 attended meeting]; two of the initial members have left the group. There was opportunity to discuss the issues that arose during the meeting and the following action plan was put forward:

Claims

The project team is an already established multidisciplinary group of healthcare professionals with a special interest in meeting the needs of hospice patients with dementia, learning disabilities and mental health concerns. It was generally recognised that the project had raised the profile of the group: 'the group members are used as links on the ward and can be approached by other staff members for guidance and support'. The other benefits identified were having a tool (the 'Helping Us Understand You' booklet) and a variety of easy to access resources to support staff in caring for people with cognitive impairment. It was also suggested that it 'shows the hospice has an awareness and keenness to help patients with cognitive impairment'. One person commented that 'it will give evidence to the Quality Care Commission when they ask us how we know we are meeting the patient’s needs'. The day/night calendar clock and pictures to share books were the resources identified as being most used. The other resources mentioned were the stress balls, DVDs and the pictocom book.

Several examples of good practice were identified:

'The booklet was used with a patient who had dementia cared for at home. The family did the booklet together and it enabled them to leave it for the carers when they were not on the scene, life history gave talking points and likes and dislikes gave stimulation eg music and TV. It was a great help for carers who did not know their mum.'

'A patient was admitted to the hospice who could not communicate with staff so I spent time with the family to fill out the 'Helping Us Understand You' booklet. The family were very happy with this.'

'Deprivation of Liberty Safeguards (DoLS) assessor attended the hospice to assess a patient who had a brain tumour. Despite the DoLS being in place the assessor must ensure that an organisation takes all possible steps to provide care to this patient in the least restrictive manor. The hospice was commended in this respect. The patient had been a keen cyclist so the physiotherapy department provided their exercise bike so he could continue to cycle using this.'

Concerns

- Having the time to give the booklet 'Helping Us Understand You' to patients and families and going through it with them.
- Ensure that everyone one is aware of where the 'Helping Us Understand You' booklet and the
resources are kept.

- There are still members of staff who do not readily consider using the resources or the experience of the project team members.
- The resources are limited and are not always appropriate for our patients when their end of life needs out-weigh their communication or other cognitive difficulties.
- The project group is predominantly from the nursing and healthcare assistant staff. Widening the membership of the group would encourage more people to promote the work.
- More resources are required which need to be equally distributed on both wards.
- More time is needed for the group to confidently work together to implement and share knowledge.
- Difficult for the project group to attend meetings together due to the work load and staff shortages.
- Completing the booklet should not become a form filling exercise rather than an on-going process. Some patients have difficulty filling out forms or do not like to write things down.
- People’s expectations may be too high regarding what can be achieved.
- Concerns that it is not used enough in the community, if used it could help staff on the inpatient unit if patients are admitted.
- Concerns that the booklet and resources are used inappropriately and pressure put on patient and family at a time they are stressed.
- If the booklet is being completed by the patient and family then it is necessary to make sure it stays with them but MDT members look at the information.

<table>
<thead>
<tr>
<th>Action</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>The names of the project team members to be displayed in appropriate areas</td>
<td>To ensure people know who they are and how to contact them</td>
</tr>
<tr>
<td>Put a proposal forward to develop the 'Helping Us Understand You' booklet in a more robust format. Encourage the patient to keep it with them and carry it with them if they change care environment and for all members of MDT to read it</td>
<td>Currently it is printed on A4 pages stapled together. A more robust booklet form could be kept with the patient. On the in-patient unit it could be kept separate to other folders in a place where everyone, patient, family, staff can read and add to it. If it is completed when the patient is at home or when they come to day hospice it can be carried with them. A more robust form will better withstand being carried about</td>
</tr>
<tr>
<td>Put a proposal forward to get project team members dedicated time to disseminate the work</td>
<td>With dedicated time they could work with the patients and families to support them to fill in the booklet, organise the appropriate resources for patients, give ward based teaching and present at ward meetings</td>
</tr>
<tr>
<td>Put a proposal forward to flag up when a patient has a 'Helping Us Understand You' booklet. This could entail developing an area to record it in the patient’s electronic record. On the inpatient unit it could be identified on the MDT handover sheet.</td>
<td>To encourage and remind patients to keep the booklet with them if admitted or discharged to hospice, hospital or care home. To avoid staff offering it to them if they have already done it earlier</td>
</tr>
<tr>
<td>Develop a care plan for patients with difficulties communicating their needs</td>
<td>This will encourage staff to assess for offering the 'Helping Us Understand You' booklet and appropriate resources and to document this. This</td>
</tr>
</tbody>
</table>
will then be reviewed on a regular basis

<table>
<thead>
<tr>
<th>Celebrate good practice</th>
<th>Develop a display of examples of good practice to acknowledge the positive outcomes of the project and encourage further engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitor the use of resources and put a proposal for the purchase of those identified as most useful</td>
<td>Share resources between both wards and advertise them for community and day hospice use</td>
</tr>
</tbody>
</table>

**Discussion**

*A person-centred approach*

When this project was originally considered, it was based on improving the assessment of pain and distress in hospice patients with cognitive impairment. There are numerous behavioural assessment tools developed for use with people who are unable to communicate verbally. Many of these call themselves pain assessment tools when they are actually detecting the presence of distress which may have physical, social or emotional causes (Downs et al., 2006). The second concern is that the efficiency of these tools is based on their psychometric properties of reliability and validity. Studies suggest however, that different carers identify different behavioural cues for an individual because of relationship differences (Regnard et al., 2007). This might explain why the authors of a systematic review of systematic reviews (Lichtner et al., 2014) were not able to advise the use of one tool over another based on their psychometric properties. It is argued by some that rather than standardising the assessment process, a more accurate and broader picture of someone's distress may be achieved by using a variety of methods carried out by a number of people with different relationships with the person with cognitive impairment (Regnard et al., 2007; Snow et al., 2004), arguably a person-centred approach. Through a literature review (Chatterjee, 2012) the project lead advocates the DisDAT (Regnard et al., 2007) a behavioural assessment tool which offers a systematic and person-centred approach to allow healthcare professionals, carers and families to identify and document a person's distressed behaviour.

To begin with however it was necessary to take a step back. Patients are admitted onto the in-patient unit of a hospice for the holistic assessment and management of symptoms. For patients with cognitive impairment, an unknown environment and unfamiliar carers can create confusion and distress. A priority therefore is for healthcare professionals to provide care in a way that avoids or limits undue distress. Understanding the person's normal habits, routines, likes, dislikes and life history can support staff to give reassurance, security, understanding and validate their life through the provision of relaxation, occupation, distraction and reminiscence. If, despite these methods a patient suffers unresolved distress the DisDAT can then offer a more structured approach to determining the cause.

Phase one of this project therefore looked to embed the foundation of person-centred skills into practice through the development of the *Helping Us Understand You* booklet, the acquisition of appropriate resources and the study day workshop on 'the experience of cognitive impairment'. Person-centred care is integral to palliative care and as one participant of the workshop study day suggested, it is already embedded into palliative care practice. The study day workshop made apparent the difference between person-centred care for those with autonomy and choice and those that lack decision making capacity. Generally participants felt it useful to understand the difficulties that people with cognitive impairment experience and ways they can support them including the importance of adapting the way they communicate and manage the environment. Evaluations of the study day workshop completed after nine months suggested there was a level of knowledge retained and participants continued to express an empathy and understanding of the needs of people with cognitive impairment.

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When developing the ‘Helping Us understand You’ booklet, it was decided to give prompts to help patients and their families understand what information would be most helpful. One prompt sums up the person-centred nature suggesting the importance of knowing ‘the little things that make you comfortable’. There was concern that prompts may be seen as too prescriptive but both the patients who completed a booklet as a pilot said they were useful and reported that they would have found it difficult to know what to put without them.

When patients are admitted to the in-patient unit, this is likely to be at a time when they are experiencing deteriorating health and they will often rely on their families to complete the ‘Helping Us Understand You’ booklet for them. Families will be stressed and as a member of the project team pointed out, not all families are sufficiently close to be the patient’s true advocate. This was confirmed by one patient who piloted the booklet. She said her best friend would be able to give more reliable information than her family. Ideally the booklets could be completed by patients and their families at home or in the day hospice prior to any admission to the hospice. This way it could be done over a period of time when there was less stress.

The choice for patients and families on whether they want to complete the booklet and the information they wish to share is highlighted at the front of the document. It is important that there is no pressure felt to complete it otherwise it will become just another paper exercise and lose its person-centredness. This was a concern highlighted by the project team suggesting the process be ongoing with information being added as it comes to mind which may often be when families and patients are in conversation with staff. It was further highlighted by a carer who was asked about it and by members of the project team, who said that not everyone can or wish to write out the information. Staff therefore need to find out whether the patient/families require help in this respect.

A person-centred approach also relates to providing leadership to staff. Staff need to feel valued and engaged to deliver practice change. Asking staff on the study day workshop to reflect on their practice helped them to see the positive skills they already exhibited. Encouraging the project team to participate in delivering the sessions identified to others that they had the knowledge, skills and experience to champion the work in practice. The participants appeared enthusiastic and motivated following the study day workshops. There were no negative descriptors identified by the end of day evaluations; the descriptor used most was ‘thought provoking’ which would appear to suggest that staff value reflective practice. A senior nurse suggested that to give staff encouragement and a sense of achievement it would be good to celebrate success through a display that evidences best practice.

**Scope of the project**

Although the primary aim of the project was to improve the care of patients with cognitive impairment there are other hospice patients who may have difficulty expressing their needs who could also benefit from person-centred approaches such the ‘Helping Us Understand You’ booklet. This would include people with dysphasia or extreme frailty and fatigue.

Many palliative care patients have insight into their illness. Understanding there may be a time when they need admission to a hospice or hospital, they may wish to complete the booklet for themselves while they are still well enough to do so. This would make the booklet appropriate to all palliative care patients who choose to complete it. As one of the project team suggested, by introducing it to patients at an early stage it could gently open up conversations about the end-of-life and initiate advance care planning.
Implementation of practice change

This project's aim was to introduce the 'Helping Us Understand You' booklet into practice to support staff care for patients who have difficulty in communicating their needs in a way that is individualised and avoids or minimises their distress. Staff attended training in understanding the specific needs of people with cognitive impairment and the importance of knowing as much as possible about the person. Furthermore resources were put in place to help staff provide appropriate activity, occupation, distraction, reminiscence and to support communication with these patients. This would suggest a small change in practice but as one member of the project team identified at the beginning 'it could be difficult and lengthy'.

Time was identified by many as a main barrier. Dedicated time for members of the project team to attend meetings and facilitate the initiative in practice; time for members of staff to discuss the use of the booklet with patients and families and in some cases to fill it out with them; time for patients and families to engage with the booklet particularly when they had been admitted as an in-patient to the hospice and there are a lot of other changes happening for them; time for patients and families to engage with the booklet particularly when they had been admitted as an in-patient to the hospice and there are a lot of other changes happening for them; time for members of the MDT to read the information and instigate the use of appropriate resources. Through discussions and training, staff can be helped to understand that a little time spent initially could save a lot of time and energy in the long run by avoiding untoward distress in patients and being more able to understand their needs. Introducing the booklet at the earliest stage, ideally while a patient is cared for in community or the day hospice, would help staff on the inpatient unit. Promoting it as an ongoing process rather than a one off tick box exercise to get it all filled out, could help it become part of a culture of relationship building between the patient and their families and staff which allows appropriate information to be shared in a way that does not feel burdensome.

Communication was another major issue that hindered this project. The hospice was undergoing a restructure and established teams and lines of communication were changed and new ones were being developed. This made the dissemination of information about the initiative less effective to begin with and it took time for the project to build momentum. However, towards the end of the project it was recognised by several members of the project team that the profile of the project team and their work had been raised. Due to issues around staff shortages and time for staff to be released from regular duties it was not possible for the project team to hold regular meetings. Practice development relies on team work and a cyclical process of review and action planning. The project lead did what could be done to keep everyone informed but people received information at different times and one to one discussions made the process less democratic. This meant that it was difficult to coordinate the dissemination of information to staff and it seems likely that this had a negative effect on the project’s impact with a lack of a clear message at times.

The study day workshops were evaluated well and the participants appeared to have gained an understanding of some of the specific needs of people with cognitive impairment which seems to have remained with them nine months post training. The values and beliefs clarification exercise is a practice development exercise which brought about a shared understanding of person-centred care. This gave a platform to further develop the concept throughout the day in relation to people with cognitive impairment. For a change in workplace culture to effectively occur a significant number of staff need to take the understanding and concept forward. The study days reached 19 of a total of approximately 250 clinical staff within the organisation with a further 18 staff given a shorter introduction during a 1.5 hour session on their mandatory training. Time to release staff for training was an issue with one study day workshop being cancelled due to staff shortage. It was suggested through the end of day evaluations that such a session should be part of the mandatory training process rolled out each year. If this was the case it would be kept on everyone's agenda.
Originally, the project team had planned to carry out a claims, concerns and issues (CCI) exercise on a monthly basis with the project team itself and then additionally, at significant stages in the project by members of the senior clinical team. This was to promote rigorous action planning and maintain the engagement of senior clinical staff who, in their leadership roles, are vital for overseeing the project roll-out. Over the 18 month course of the project the project team met twice to participate in the CCI exercise and senior members of the clinical team were involved in the final one. Clear action plans have been developed out of each of these exercises which have given an understanding of what the project has achieved to date and how it should move forward. At the time of writing this report, it is only two months since the roll-out of the use of the ‘Helping Us Understand You’ booklet in practice across all departments. The tool at the time was used predominantly on the in-patient unit and for people with cognitive impairment. It could be suggested that at the time it was too early to evaluate it. The project has taken time to build up momentum but the project team plan to continue with further CCI exercises which will help to determine the course and firmly implement the practice changes.

Conclusion
Practice development is concerned with embedding person-centred care initiatives into practice. Joining the Patients First Programme at the Foundation of Nursing Studies gave clarity and support to the project. Attending the first study days helped the project team set out the aims of the project and it became clear that although it was originally aimed at supporting hospice patients with cognitive impairment, such a person-centred approach could be applicable to the wider palliative care population who are, or at risk of, experiencing difficulty expressing their needs. In line with a person-centred approach, the project tried to remain inclusive and democratic involving key stakeholders including staff representing the multi-disciplinary hospice team, lead clinicians and patients and carers.

The main difficulty experienced by the project was the difficulty in getting staff released for workshops and to attend meetings and this meant the project took time to build up momentum. In the final months of the project time scale the ‘Helping Us Understand You’ booklet was rolled out across the hospice departments, resources are available and being used by patients on the in-patient unit and a significant number of staff have attended the ‘experience of cognitive impairment’ workshops. As a project lead, the energy, persistence and enthusiasm needed for practice development became apparent. A project lead could be likened to a dog with a ball, which it persistently and expectantly leaves at someone’s feet hoping that they will pick it up and throw it out to a wider audience.

Implications for future practice
Through the work of the project and with the support of the FoNS team, the profile of the work of the project team has been raised considerably. The latest CCI excise identified a clear action plan to embed the ‘Helping Us Understand You’ booklet and use of resources in practice, this will include getting members of project team dedicated time to facilitate the process. Off shoots from this project have also developed these include:

- The hospice has run the Enhanced Healing Environment Assessment (King’s Fund, 2014) and is looking at a business plan to ensure the environment is suitable for people with cognitive impairment
- The hospice will collaborate with the School of Dementia Studies at the University of Bradford to deliver Peer Facilitator Dementia Care Training at tier one and two to be rolled out across six hospices in the region including St. Gemma’s Hospice
- Two bespoke study days on supportive and augmentative communication techniques will be run for hospice staff by a speech and language therapist/dementia care trainer from the University of Bradford
• The project lead has completed training sessions on the use of the DisDAT to the hospice community team and the medical staff. With the support of the project team it will be rolled out to other clinical staff through small group ward-based teaching.

These will reinforce and continue to add to the progression of the project and lead the development of phase two. Regular CCI exercises with the project team and key stakeholders are expected to provide continuous review, action learning and evaluation of all the activities as they develop.

References


Appendix 1

This is me

This leaflet will help you support me in an unfamiliar place.

Please place a photograph of yourself in the space provided.

My full name

Guidance notes to help you to complete This is me

Name I like to be called

Where I live

Contact person who knows me best

I would like you to know

My life story (family, home, background and treasured possessions)

Current and past interests, jobs and places I have been

The following routines are important to me

Things that make me feel better if I am anxious or upset

My medication

My eating and drinking

Other notes about me

Date completed

Relationship to person

I agree that the information in this leaflet may be shared with health and social care professionals.

For someone with dementia, changes such as moving to an unfamiliar place or meeting new people who contribute to their care can be overwhelming. This is me provides information about the person at the time the document was completed. It can help health and social care professionals build a picture of the individual and support them in their work.

This is me should be completed by the individual who knows the person best and, wherever possible, with the person with dementia. It should be up-to-date and reviewed regularly. It is not medical assessment.

On the back page you will find more detailed guidance notes to help you complete This is me, including a list of the best information to include. You might find it helpful to read through these notes before you begin to fill in the form.

For more information on this leaflet please call 01234 567890 or email dementiacare@nhs.org.
A note from the Hospice staff

This booklet aims to help us support you if you feel too frail or weak to tell us about yourself or if you have some difficulty in communicating how you feel.

It is designed to allow you and those who know you well, to provide us with information that will help us care for you in the best possible way. Appropriate information can help us to anticipate your needs.

This booklet belongs to you and your family. The following pages will offer advice on the kind of information that will help us to care for you as an individual. It is for you to choose the amount and type of information you give us.

My name is: ........................................

I like to be known as: ...........................

People, pets, places and things that are important to me:
Example- who might you want to speak to if you are upset; are there personal items you wish to keep with you at all times.

My normal routines and habits:
Example - morning and bedtime routines; specific times or days when you do certain things. Although illness may prevent you from continuing with some of these, knowing about them will help us to get a sense of how you may be feeling at particular times.
My likes and dislikes:
Example- food and drink, clothes, TV, music, hairstyle, soaps and perfumes, colours. Things that cause me to become anxious and distressed:
Example- family concerns; physical symptoms of pain, feeling sick, difficulty in going to the toilet; environmental issues such as too much noise, being left alone, too many people in the room, bright lights, door open/closed.

How might you know when I am anxious or distressed:
Example- withdrawn, angry, pacing about, rocking, facial expressions, body posture.

Things that help me feel better and help me relax:

Other things to know about me:
Example- your personality; values; religious beliefs and practices; physical support needs; communication support needs; how you take your medication; the ‘little things’ that help you feel comfortable.

My life story:
Example- important events; family; work; hobbies and interests. Insight into your past can help us understand and respect you as a person. This can be enhanced if you have photographs from your past with you.

I am happy for the information in this booklet to be shared with members of the multidisciplinary healthcare team who will be involved in my care.

Patient’s Name .............................................................

Signature: .................................................................

Or

Patient Advocate

Name: .................................................................

Relationship to patient: ............................................

Signature: .................................................................

Date: .......................................................
Appendix 3

Carer Information

‘Helping Us Understand You’ booklet

This booklet aims to help hospice staff support your loved one if they feel too frail or weak to tell us about themselves or if they have some difficulty in communicating how they feel.

It is designed to allow them and those who know them well, to provide us with information that will help us care for them in the best possible way. Appropriate information can help us to anticipate their needs and avoid causing them undue distress.

I would be grateful if you would consider completing the booklet. Once you have looked at it I would like to meet with you and discuss:

• your thoughts about being asked to complete it
• how you think it would help hospice staff in providing care
• if you feel the images and wording used are appropriate
• if you feel there is anything else that should be included

This study is being undertaken as part of the ‘Patients First Programme’ supported by The Foundation of Nursing Studies in partnership with the Burdett Trust for Nursing. The information I obtain may be published at a later date. Confidentiality will be maintained. You are free to withdraw your contribution from this study at any time. If you have any questions or concerns now or in the future please contact me.

Yours sincerely

Jane Chatterjee- Lecturer in Palliative Care

St. Gemma’s Hospice

329 Harrogate Road, Moortown, Leeds, LS17 6QD, UK

Tel: 0113 218 5500    janec@st-gemma.co.uk

Patient Information
Appendix 4: Letter to Patients

‘Helping Us Understand You’ booklet

This booklet aims to help hospice staff support you if you feel too frail or weak to tell us about yourself or if you have some difficulty in communicating how you feel.

It is designed to allow you and those who know you well, to provide us with information that will help us care for you in the best possible way. Appropriate information can help us to anticipate your needs and avoid causing you undue distress.

I would be grateful if you would consider completing the booklet. Once you have looked at it I would like to meet with you and discuss:

• your thoughts about being asked to complete it
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• if you feel the images and wording used are appropriate
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Yours sincerely

Jane Chatterjee- Lecturer in Palliative Care

St. Gemma's Hospice

329 Harrogate Road, Moortown, Leeds, LS17 6QD, UK

Tel: 0113 218 5500  janec@st-gemma.co.uk
### Appendix 5: The workshop time table

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.00- 11.00</td>
<td>Introduction, Values and Beliefs Clarification Exercise, PowerPoint presentation</td>
<td>Project lead</td>
</tr>
<tr>
<td>11.00- 11.30</td>
<td>Coffee</td>
<td></td>
</tr>
<tr>
<td>11.30 -12.30</td>
<td>Part 1 - Supporting a patient with cognitive impairment: a case study</td>
<td>Project team members- Occupational therapist, Complimentary therapist</td>
</tr>
<tr>
<td>12.30-13.45</td>
<td>Lunch and Displays and Activities</td>
<td>Project team members- Nurses and Healthcare assistants</td>
</tr>
<tr>
<td>13.45-14.45</td>
<td>Part 2 - Memory and Behaviour</td>
<td>University Professional Lead Mental Health Nursing</td>
</tr>
<tr>
<td>14.45-15.45</td>
<td>Part 3- Person-centred care: what does it mean for someone who has lost their decision-making capacity.</td>
<td>Project lead and project team member-social worker</td>
</tr>
<tr>
<td>15.45-16.30</td>
<td>Claims, Concerns, Issues exercise Concluding thoughts Evaluations</td>
<td>Project Lead</td>
</tr>
</tbody>
</table>
The Experience of Cognitive Impairment

Objectives:
- To gain an understanding of the experience of patients with cognitive impairment and how this may reflect in their behaviour.
- To gain an understanding of how we can support the needs of patients with cognitive impairment.

The topics that will be covered:
- The brain and behaviour
- Memory and behaviour
- Person-Centred Care: what does it mean for those who have lost their decision-making capacity
- Activity, occupation, environment.

There will be a demonstration of Mindset resources

Target Audience: All hospice staff involved in the care of patients are welcome to attend

Facilitators: Jane Chatterjee- Lecturer in Palliative Care
Members of Mindset

Guests: Julia Turner- Professional Lead Mental Health Nursing, University of Leeds
Jo Odel- Practice Development Facilitator, Foundation of Nursing Studies

Dates: Thursday 10th July 2014

Time: 09.00am-16.30pm

Venue: Academic Unit of Palliative Care, St Gemma’s Hospice

Booking: Please contact Carolyn Shepherd Ext 2001 if you would like to attend this workshop
Appendix 6

Case Study

Mr Smith, a gentleman with prostate cancer and dementia, was admitted to the hospice for assessment and management of his pain. Changes in his analgesics meant that his pain became better controlled.

He continually expressed the wish to return home. His wife Brenda was his main carer and she had become too unwell to continue to care for him. He was unsafe to be left on his own even for short periods of time. On assessment it was deemed that Mr Smith lacked capacity to make this decision and acting in his best interests healthcare professionals and his family made plans for his discharge to a care home.
Appendix 7: Staff leaflet to help implement 'Helping Us Understand You' booklet

Implementing the 'Helping Us Understand You' you booklet - Staff information leaflet

Which patients could the booklet appropriately be used with and when should it be given to them and/or their family to complete?

It could be useful for anyone who has or may develop difficulty expressing their need which could be any hospice patient. This may be because they have cognitive impairment, dysphasia or extreme frailty and fatigue.

It may be completed by the patients themselves at a time when they are well enough to do so. This may be for patients who have insight into their illness and recognise that they will become less well and may require admission into a healthcare environment (hospice or hospital)

It may be completed with the support of the family or by the family on behalf of the patient if they are not able to complete it themselves.

Ideally it would be completed in the community or day services prior to any admission to the hospice and brought in by the patient but it can be started on the ward if this has not happened earlier.

How do we approach patients and families to ask them to fill in the booklet?

On the in-patient unit a blank copy will be kept in the end of bed folder. Patients and families are made aware of it and given an explanation of how it can support patient care. In the community and day services staff can promote its use in a timely way. It may act as an introduction to more structured advance care planning discussions.

Patients and families are free to opt out of filling it in and should be made aware that it is entirely up to them what information they give and what they leave out.

It may not be apparent straight away what information is useful. Patients and families may pass on useful information in general conversation with staff. Staff can ask permission to include it in the booklet.

What do we do if patients and families have difficulty with reading and writing or just find it too stressful to complete the booklet?

It does not need to be completed straight away but over a period of time. Some people may have difficulty reading or dislike filling in forms and may want staff to write the information down for them. Staff need to check if this is the case.

How do we support a patient who is not able to communicate their needs if their family does not know much about their routines, likes and dislikes etc?

Staff and family can fill in the information over time as they get to know the patient more. Staff could look for the information from other sources such as the district nursing notes and System one.

How do we encourage all members of the multidisciplinary team to implement and use the booklet appropriately?

It should become routine for all members of the MDT to look in the end of bed folder to see if the booklet is in use.

It is the patients’ property. Although there is a section for the patient or their advocate to sign to say they are happy to share the information with the MDT it is good practice to ask permission when feasible.

Patients and families are encouraged to keep the booklet with them on discharge or admissions to the Hospice/hospitals.
Appendix 8A

Words and Pictures

- Written words and pictures support the comprehension of the spoken word

- Helps people with communication difficulties to stay focused on a topic and reduces demand on their memory and language skills
Appendix 8B

Supportive Communication Tips

- Summarise a conversation and seek confirmation that you are right about any assumptions you have made about what has been said
- Keep conversation as simple as possible without being patronising or sounding childish
- Questions that require a yes/no answer are easier to answer than questions that ask ‘why’
- Use gestures and visual prompts
- Talk at a slower pace so that the person has time to grasp what is being said
- Minimise distractions
- Address sensory impairments
- Get to know as much as you can about a person’s life stories, values, likes and dislikes to pick up on conversational and behavioural cues and to initiate conversations

- Pay attention to a person’s non-verbal communication
APPENDIX 8C

VISUAL PERCEPTUAL DIFFICULTIES

Although the person may still have good eyesight, they may experience problems in recognising what they see.

They may experience a decreased ability to perceive colour contrasts and depth.

**Overload** - too much information coming at the person for them to process it and make sense of it.

**Out of Sight Out of Mind** - things outside of the person’s visual field are not perceived as present or in the person’s awareness.

**Tunnel Vision** – narrowing of the perimeters of the visual field (peripheral vision)

**Visual Cliffs** – dark or black surfaces are perceived as cliffs or holes

**Depth Perception Problems** – items that don’t have much contrast are perceived as being continuous; patterns or colour contrasts are perceived as having different depths even when they don’t. Sudden changes in floor colour or covering can be misinterpreted as change in depth.

**Preoccupation with Small/Busy Patterns** – small prints may seem to resemble lint or bugs, the person may try to remove them from the fabric. Busy patterns can be confusing or cause sensory overload resulting in agitation, preoccupation or repetitive behaviour.
Difficulties of communication, concentration, memory and co-ordination:

- make it difficult to seek and carry out social and recreational activities
- cause restlessness, agitation or withdrawal through lack of stimulation and occupation
- cause feelings of boredom, worthlessness and social isolation

Rummage

Simple repetitive activities that have been learnt over a lifetime remain achievable for longer. These include activities such as sorting, folding, polishing, dusting, dismantling, unravelling knitting, peeling vegetables.

Stimulation of visual and tactile senses can enhance wellbeing

Clues about what may be most effective can be taken from a patient's past history of work and hobbies.

Care should be taken that the activity is safe and achievable for the individual.

Reminiscence

Short-term memory problems make it difficult for people to negotiate and discuss current issues affecting their daily lives.

Memories of the past remain intact for much longer and can give people a sense of worth and wellbeing to talk with fluency and authority about the past.

Reminiscence is also a way of validating someone’s life.

Not all memories are happy ones sensitivity is needed and awareness of any topics that cause a person distress
Appendix 9A

Understanding what people do

People with dementia may ‘act out’ feelings or needs in non-verbal ways, particularly where speech is limited. Such actions are often thought of as ‘problem behaviours’, but can perhaps be better understood as ‘non-verbal metaphor’. Life history material can help us understand the messages in behaviour.

Doris spent a lot of time in the residential home collecting towels, bedding and clothing. This ‘pilfering’ was awkward for staff, as Doris picked up things belonging to other people. When they found out that Doris had worked as a seamstress, and had made all her children’s clothes, they understood what she was doing and could see a way to solve the problem. The family still had some of the dresses she had made. These were put into a box with a number of lengths of material in various designs and textures. Staff encouraged Doris to handle and fold the materials, and in this way the ‘problem behaviour’ was transformed into a pleasurable activity.
Appendix 9B

The past in the present

Traumatic experiences
Memories of traumatic experiences are deep-rooted and can re-surface at unexpected moments. In Bill’s case the stress of being admitted to hospital and being in a strange place probably made it more likely that he would misinterpret what he was seeing around him - with the result that his terrifying childhood memory was triggered.

*When Bill Bates went into hospital for treatment he seemed to understand why he was there, and was generally co-operative except when getting up in the mornings. From the moment that staff helped him to sit up in bed, he became very aggressive, and lashed out at anyone who came near him. A nurse specialising in dementia tracked this behaviour down to the shiny blue lino floor. In the mornings, this floor caught and reflected the light from the window, making it look like water. As a small child Bill had been thrown into a swimming pool and nearly drowned. When he sat up and saw the lino floor, it looked to him just like the surface of a pool, and he was determined to prevent the nurses from throwing him into the water. When Bill was moved to a room with a dull brown floor, his aggressive behaviour ceased.*
Appendix 10

Helping us understand you

Providing Person-Centred Care: Knowing the person

- Understanding a person’s normal routines, habits, likes and dislikes can help to maintain their personhood and avoid unnecessary distress

- Knowledge of a person’s ‘life story’ can create empathy and a therapeutic relationship of trust

- Knowledge of significant people, pets, places, events and life history can help develop an understanding of an individual’s reality and respond to their emotions
Appendix 11

Person-centred Care at
St Gemma’s Hospice
Helping us understand you

We have a booklet that can be filled out by you and/or your family to help us get to know you and the things that are important to you.

For more information please speak to a member of the nursing team.

Registered Charity No. 1015941