



Somerset Dementia Collaborative: An Evaluation of a Humanising Care Approach

Marilyn Cash, Kathleen Galvin, Les Todres
September 2011

Acknowledgements

We would like to thank the two Project Facilitators who were central to the initiative and to informing our evaluation.

Contents Page

Executive Summary.....	5
Introduction	5
Somerset Strategic Improvement Fund (SSIF) Dementia Project Group.....	5
Implementation of the Project	6
Lived Experience Workshops	7
Ward Based Projects.....	7
The Somerset Collaborative for Dementia Care Workspace on Huddle.net	10
Approach to the Evaluation	10
Findings	11
Initiatives that have emerged from Ward-Based Projects.....	13
The Somerset Collaborative for Dementia Care Workspace	14
Recommendations	14
Conclusion.....	15
Introduction	17
Context for the Project	17
SSIF Dementia Project Group.....	22
Steering Group Terms of Reference and Aims.....	23
Rationale for Evaluating the Project	24
Description of Project Sites.....	25
Implementation of the Project	26
Humanisation Framework	26
Lived Experience Workshops	30
Ward Based Projects.....	32
Huddle Network.....	34
Approach to the Evaluation	36
Interviews.....	36
Self-Completion Questionnaires.....	37
Lived Experience Workshops Evaluation Questionnaires.....	38
Ward Projects Evaluation Questionnaires	38
‘Post-it-Note Feedback’ from Lived Experience Workshops.....	39

Evaluation	40
Lived Experience Workshops	40
‘Post-it-Note Feedback’	40
Communication.....	41
Time	41
Humanising Practice	42
Training	42
Results from Lived Experience Workshops Questionnaires	43
Ward-Based Projects.....	50
Ownership.....	50
Better communication with carers and family members	51
The ‘little things’ we have changed	52
Engaging with patients with dementia	53
Initiatives that have emerged from Ward-Based Projects.....	53
Barriers.....	56
Results from Ward Project Questionnaires	58
Environment Projects	65
Carers Projects	69
Occupation Projects.....	71
The Somerset Collaborative for Dementia Care Workspace	74
Summary and Conclusions.....	75
Recommendations	76
Conclusion.....	77
References	80
Appendix 1: Example of a Ward Action Plan	82
Additional Questions for Staff Participating in a Ward-Project relating to Occupation.....	94
Appendix No 3: Communication Booklet.....	96
Appendix No 4: The humanization of healthcare: A value framework for qualitative research	102
Appendix No 5: Presentation Slides from the Celebration Day.....	112

Executive Summary

Introduction

This document reports on the work of the Somerset Collaborative for Dementia Care Project that ran for a year from April 2010 until March 2011. The project was initiated to improve hospital care for people with dementia and their carers. Two members of staff were recruited to facilitate the project which involved working with staff from the thirteen community hospitals and two general hospitals situated in the county of Somerset. Based on a philosophy of attending to the 'human dimensions of care' (Todres et al., 2009) the project involved three strands -:

- Lived Experience Workshops, designed to support staff to experience the difficulties that patients with dementia face on a hospital ward.
- Ward-Based Projects that allowed staff to adopt a project aimed at enhancing the experience for the person with dementia and their carers and family members.
- An on-line platform for staff to exchange ideas and good practice.

Somerset Strategic Improvement Fund (SSIF) Dementia Project Group

The SSIF Dementia Project, a multi-agency initiative was set up to focus on dementia training in order to develop the skills and knowledge of staff to enable better and more effective working with people with dementia and their carers. The SSIF Dementia Project Group agreed to move away from traditional models of learning and achieving change by being innovative in its approach to the project. Together with Bournemouth University the group worked to develop a programme for staff that would support them to work with dementia patients, families and their carers by: -

- providing practical learning and support
- working with them to develop practice

- providing sustainable learning opportunities

To achieve these aims a multi-agency Dementia Collaborative for Somerset was set up and was led by a Steering Group. The Steering Group was comprised of senior and relevant members of staff from Somerset Partnership NHS Foundation Trust, NHS Somerset, Somerset Community Health Trust, Taunton and Somerset Foundation Trust, Yeovil District Hospital Foundation Trust, Bournemouth University and the Alzheimer's Society.

Implementation of the Project

Two members of staff were recruited to lead the project they were selected because of their experience of working with patients with dementia and for their passion to improve dementia care.

The approach that the facilitators took moved away from the more traditional didactic form of teaching with its tendency to focus on the biomedical model of dementia, towards a model that focuses on the humanising aspects of care, where the patient is seen as a human being and, not just a diagnosis. In particular staff were asked to consider the challenges patients with dementia might face when coming onto their ward *rather* than the challenges the staff themselves might face. As the following report will demonstrate, this approach offered staff a unique experience, by drawing on the humanisation framework, and this allowed them to 'see the world from a dementia person's eyes'. This empathic oriented approach to learning, worked on an emotional rather than an intellectual level, and there is some evidence that the strategies used in this project facilitated new understandings for staff. A key feature concerns how strategies emerged rather than being directed from top down.

Lived Experience Workshops

Workshop sessions were designed to support staff to see the patient with dementia as a *person* rather than a '*diagnosis*' in order to allow them to deliver personalised care based on the principles of the humanisation framework that has been developed by Todres, Galvin and Holloway (2009) at Bournemouth University.

The sessions began with a visualisation exercise outlined by Brooker & Surr (2005). During this exercise participants were encouraged to consider the sights, sounds, feelings and frustrations, which could be experienced by a patient with dementia who was resident on their ward. After the exercise participants were given time to explore their feelings and discuss possible solutions.

Participants were then asked to consider the challenges that patients with dementia might face when coming onto their ward *rather* than the challenges the staff themselves might face.

Engaging staff in this way invited them to step '*out of their comfort zone*' into the world of the patient with dementia allowing them to experience and reflect on the challenges facing patients with dementia in a busy ward environment.

Ward Based Projects

In order to engage on a practice level with ward staff the project facilitators devised a number of ward-based projects. The themes for the ward-based projects were chosen by the project facilitators based on, 'their recurring appearance in both Department of Health and Alzheimer's Society publications'.

Six themes all underpinned by the human dimensions of care were identified: -

- Improving nutrition

- Minimising the use of anti-psychotic medication
- Improving the environment
- Enhancing meaningful occupation
- Enhancing Person Centred Care
- Involving and Engaging Family Carers

The aim was to work closely with small groups of staff to achieve 'something tangible and something that conceivably could be rolled out', within the time-scale of the project. In liaison with the hospital dementia leads, ward sisters/managers were invited to take part in a ward-based project, to select the theme they wanted to explore and to decide who would become involved in the project, with the only stipulation being that all levels of staff should be given the opportunity to participate.

Eleven wards chose to participate in a ward-based project. Participating wards selected the following topic areas: -

- Enhancing the environment in such a way so that people feel more at home(3 wards)
- Enhancing meaningful occupation so that people feel more connected to what matters to them(3 wards)
- Involving and engaging family carers so that they have more say (3 wards)
- Enhancing person centred care (2 wards)

Introductory sessions took place on the ward with a cross section of staff. The project facilitators outlined key research associated with each of the themes, using the humanising framework as a basis for discussion with the staff. The sessions were designed to build upon existing staff expertise. Each ward was invited to draw up an action plan and these were then reviewed with the ward staff and the project facilitators over the succeeding months. (See Appendix 1 for an example of a ward action plan).

A carer who had experience of both General and Community hospitals was present and contributed to some of the introductory sessions. Speaking from personal experience she was able to highlight the importance of involving the carer as 'an asset and not as a pain in the butt', not only for their ability to give staff a history of the patient with dementia but also for their ability to provide support in caring for the patient with dementia.

In addition the 'This is me' booklet produced by the Alzheimer's Society was introduced to each of the participating wards. This is a simple and practical tool that provides a 'snapshot' of the person with dementia, enabling staff to see and treat each person as an individual. The use of the booklet was responsible for 'initiating' discussion with carers about their loved one.

Because of time implications it was key that each group of staff took 'ownership' of their project and responsibility for working towards the goals they set in their action plan. The project facilitators highlighted that what the project had: -

'allowed them (staff) to do, and the hierarchy have allowed them to do, is initiate change and to take control of things themselves That's quite a big achievement because I think a lot of the time the people on the ward know what works and what can help.....people had all these ideas but they'd never done anything about it. And the fact that their organisation had put us in gave them permission to try and do stuff'.

The Somerset Collaborative for Dementia Care Workspace on Huddle.net

In order to provide sustainability after the project end an online resource was developed through Huddle.net. This was designed to allow practitioners to share information and ideas across the geographically disparate area.

The Somerset Collaborative for Dementia Care Workspace is accessed by invitation only. Invited members include: the steering group, Dementia Champions/Leads from hospitals within Somerset, staff involved in ward-based projects and staff from Bournemouth University.

The workspace is comprised of three areas: -

1. Files containing national papers, policy documents, training opportunities and individual folders relating to ward-based projects
2. Discussion Forum, where members of the group are encouraged to post topics for discussion relating to dementia care
3. A whiteboard for members to post events relating to dementia care

Approach to the Evaluation

The project has been evaluated through a mixed range of data sources including interviews with Steering Group Members and key staff involved in ward based projects, questionnaires based on the 'humanisation theoretical framework, 'post-it-note feedback', policy documents, minutes from steering group meetings and ward action plans. As this was a service evaluation there was no need for formal ethics approval, however the project team were careful to adhere to appropriate research ethical guidelines of anonymity, beneficence and informed consent.

Findings

'Post-it-note feedback': staff indicated that taking part in the Lived Experience Workshops had allowed them to '*look at a person more holistically*', and supported them to enhance their practice in a number of ways; including initiating more effective communication, taking more time with patients with dementia and, developing practice based on the recognition of the patient with dementia as a '*person and not a diagnosis*'. A number of people commented that they would like further training to enable them to support patients in the later stages of dementia.

Questionnaires: Findings showed significant gains in staff developing more confidence and awareness in working with people with dementia. As a result of taking part in the Lived Experience Workshop, and/or a ward based project staff felt they were more aware and more confident about how to: -

- Support patients with dementia to have more say in their care (Enhance Agency)
- Support patients with dementia to feel at home in the place they receive care (Enhance Sense of Place)
- Base their care on the life history of the patient with dementia (Enhance Sense of Journey)
- Help patients with dementia to feel more connected to the people that are important to them (Enhance Sense of Togetherness)
- Help patients with dementia feel that their specific needs were being met so that individualised nature of care is enhanced (Enhance Sense of Uniqueness)
- Make use of the information patients with dementia need to be given to enable them to make sense of their treatment (Enhance Sensemaking)
- Enable patients with dementia to feel that their care is directed to their well-being and not just to the alleviation of their symptoms (Enhance Sense of Uniqueness)
- See things from the perspective of the patient with dementia and respond more empathically towards them (Enhance Insiderness)

Questionnaire findings also showed some gains in relation to staff development specific to the ward based project. For instance, staff engaged in projects to enhance the environment, were more aware of environmental impacts on people with dementia. Staff involved in ward based initiatives, to improve the level of meaningful occupation for people with dementia were more aware of how providing structure and opportunities could enhance the care and well-being of people with dementia. Staff engaged in ward based projects that aimed to increase the engagement and involvement of family carers were more aware of the importance of listening to carers, the need to pass on information in an appropriate and timely way, of understanding carers stress and anxiety and how to increase carers' confidence.

Interviews: The findings were helpful in indicating important qualitative insights about the value of this approach to improving dementia care and the barriers to achieving change.

Value of this approach to improving dementia care: staff indicated how the overall project enabled them to reflect upon the needs of the person with dementia from a human perspective and to devise a rich range of ways to enhance patients' well-being from there. This gave rise to a number of initiatives that included for example memory boxes, tea parties, improved signage, communication strategies, development of picture menus.

Barriers to achieving change: A number of barriers were encountered during the implementation of the ward-based projects; these included: -

- Lack of Time
- Financial Resources
- Structural Design and Ward Layout
- Cross Department Working
- Staff Attitude

Initiatives that have emerged from Ward-Based Projects

A number of innovative initiatives have emerged from the ward-based projects that support patients with dementia in ways that are highly consistent with the eight dimensions of the humanising framework, that we elaborate on in the body of the text: -

- **Picture Menus:**
Used to inform patient's choice of meal, and enable them to exercise agency.
- **Memory Boxes**
Used to stimulate patients to recall past events and support them to engage in conversation and make sense of things.
- **Tea Parties**
Used to promote social interactions and provide cues for eating linked to past meaningful connections.
- **Coloured Crockery**
Used to alert staff that the patient might require support with eating and to support the perceptual abilities of the person.
- **Hand Massage**
Used as a form of relaxation therapy and as a way of connecting with patients as individuals in an embodied and person centred way.
- **Planting bulbs**
Used as a way of engaging patients in meaningful activity, and as a prompt for patients to recall past experiences from their life history to enhance their sense of place and sense of journey
- **Activity sessions**
Used to engage patients in a variety of meaningful activities that make meaningful connections for them.
- **Improved Signage**
Used to support patients with dementia to navigate the hospital environment.
- **Adoption of the 'This is me' booklet**
Used to provide staff with information about the patient, to enable them to see the person with dementia behind the diagnosis and to facilitate an individualised approach to care, enhancing insiderness.

- A Communication Booklet
Developed to support staff to communicate with patients with dementia in ways that are sensitive to patients' unique history and needs. (See Appendix 3)
- Volunteers reading to patient
Volunteers were recruited to read to patients to support meaningful occupation and to stimulate conversation to facilitate a sense of connection with others.
- 'Treasure boxes'
Boxes containing personal items that are significant to individual patients to support them to feel more secure in unfamiliar surroundings, provide staff with clues about the past history of the patient and, act as a medium for enabling meaningful communication, enhancing a sense of journey.

The Somerset Collaborative for Dementia Care Workspace

The workspace on Huddle.net became active towards the end of the one-year initiative and is 'very much in its infancy'. To date forty-two people have responded to the invitation to participate. Four discussions initiated by the project facilitators, have received limited responses, currently the last response was left on 5th April 2011. The project facilitators have continued to add events to the whiteboard.

It is not possible to ascertain how often the training materials have been accessed. The initiative is very much in its infancy and as such it would be premature to evaluate its success and full impact at this stage.

Recommendations

- Future staff development would benefit from further approaches to education that, are based on the framework for the humanisation of care.

- Future improvement projects recruit skilled and dedicated members of staff to lead and support ward based staff to deliver changes and new initiatives and learn together through these projects
- Encourage a move away from the didactic form of teaching to a model of staff development that is facilitative and hands on and therefore is more bottom-up and where groups of staff decide together on what can be achieved and how to achieve it.
- ‘Lived Experience Workshops’ should become embedded in the education curriculum for all staff working on hospital wards
- Further workshops could be devised to expand on the learning gained in the Lived Experience Workshops to support staff working with patients who have more advanced dementia
- Encouragement to use the information and training materials on the Somerset Collaborative Workspace ‘Huddle.net’ to initiate further ward-based projects
- To fully exploit the value of ‘Huddle.net’ and to achieve sustainability of the overall project through the projects ability to encourage practitioners to share information and ideas across the geographical areas of the Somerset Partnership
- Continued use of the ‘This is me Tool’ to support proactive communication with carers
- Further recruitment of volunteers to support ward activities
- A future study could concentrate on the sustainability and longer term benefits of the project, with a particular focus on benefit for patients and their carers and families. It is too early to evaluate this latter focus on patient benefit.

Conclusion

In the space of one year this innovative project met its aims to improve the experience of people with dementia and their carers during their hospital stay through staff training, ward change projects, and the development of an online resource.

The Lived Experience Workshops moved away from the formal approach to education by adopting a novel approach, allowing workshop participants to ‘step into the shoes’ of a person with dementia and see the person behind the ‘*diagnosis of dementia*’. This understanding has been underpinned by the adoption of the “This is me” booklet, which contains information about the person supporting staff to deliver individualized care based on the humanising strategies proposed by Todres *et al* (2009). The ward based projects were successful in facilitating a process whereby staff could creatively introduce changes in practice that had the potential to meaningfully improve experiences of people with dementia and their family members when they are admitted to a general or a community hospital.

The overall success of the Somerset Collaborative for Dementia Care Project lies in its multi-agency approach, which has seen a number of agencies coming together and working collaboratively to support the aims of project, and the two specialist project facilitators. A member of the steering group indicated that: -

‘this has been a very powerful project, and where as the outcomes around the individual wards might seem quite small, in reality what they have done is influence a much wider cultural change and focus the changing attitudes around dementia care at local level’.

Introduction

This document reports on the work of the Somerset Collaborative for Dementia Care Project that ran for a year from April 2010 until March 2011. The project was set up to improve hospital care for people with dementia and their carers. Two members of staff were recruited to facilitate the project which involved working with staff from the thirteen community hospitals and two general hospitals situated in the county of Somerset. The project involved three strands; Lived Experience Workshops, designed to support participants to experience the difficulties that patients with dementia face on a hospital ward, Ward-Based Projects that allowed staff to adopt a project aimed at enhancing the patient experience for the person with dementia and their carer and an on-line platform for staff to exchange ideas and good practice.

Context for the Project

The following section will set a policy context in order to underpin the key drivers for the overall project and its aims. In recent years successive reports have highlighted the need for an informed and trained workforce to cope with the rising number of people with dementia who require care in hospital settings.

The 2007 Dementia UK report by the Alzheimer's Society estimated that some 560,000 people in England had dementia, with a predicted rise to 600,000 people by 2010. Ageing is the biggest risk factor for dementia, and it is estimated that because of our increasingly ageing population and increasing longevity the number of people with dementia will double to 1.4 million in the next 30 years, (Alzheimer's Society 2007, Alzheimer's Society 2008). Dementia is one of the main causes of disability in later life, and although older people are particularly likely to have multiple health conditions, dementia has a disproportionate impact on capacity for independent living.

Older people are known to occupy two thirds of NHS beds and of these 40% may have dementia, (DH 2009a, Alzheimer's Society 2007, Who Cares Wins 2005). Hospital admissions can worsen the symptoms of dementia and reduce independent function permanently.

'Being an inpatient in a general hospital unit is often detrimental to the well-being of a person with dementia. It is often the case that the presence of a dementia prolongs the length of stay. This may be because treatment and therapeutic interventions can take longer, partially due to lack of staff expertise in caring for the person with dementia';(DH 2009b p:35).

In addition, people with dementia are particularly vulnerable in hospitals, because of their susceptibility to environmental change. General hospitals have particularly challenging environments for people with dementia, with cluttered ward layouts, poor signage and other hazards, (DH 2009a).

Successive reports have highlighted the shortcomings in the provision of dementia care in hospitals, (DH 2009a). 'Who Cares Wins' (2005), a report by The Royal College of Psychiatrists highlighted the importance for: -

'general care staff to recognise the impact that the presence of cognitive impairment will have for the older person's management and discharge'; (p: 19).

The National Audit Office report, 'Improving Services and Support for People with Dementia' (2007) highlighted that: -

'Half of CMHTs in our survey felt acute hospital nurses were inadequately trained in dementia needs, so in practice these patients, who need extra attention and

supervision to stop them deteriorating, may not be receiving adequate support’;
(p:10)

They recommended that dementia care training should be made a core and substantial part of the training curriculum for nurses and social care staff: -

‘..... in view of the increasing number of patients a health professional is likely to come into contact with who have dementia’; (p:13).

In response to these challenges, ‘Living well with Dementia – A National Dementia Strategy’ (DH 2009a) set out a vision for transforming dementia services. A key aim of the strategy was that people with dementia should receive high quality treatment at whatever stage of the illness and in whatever setting. In its focus on care in a hospital setting the strategy acknowledged that: -

‘There is a lack of leadership and ownership of dementia in most general hospitals. There are also marked deficits in the knowledge and skills of general hospital staff who care for people with dementia. Often, insufficient information is sought from relatives and carers. This means that person-centred care is not delivered’; (p:51).

To meet their aims in relation to ‘high quality treatment’, the strategy set out a number of objectives regarding the provision of hospital care for patients with dementia: -

- Objective 8: Improved quality of care for people with dementia in general hospitals.
- Objective 13: An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia should have the necessary skills to provide the best quality of care in the roles and settings where they work. This is to be achieved by effective basic training and continuous professional and vocational development in dementia.

Living well with dementia: the National Dementia Strategy – Joint commissioning framework for dementia (DH 2009b); set out a number of key principles for commissioning dementia services that would meet the objectives laid out in the National Dementia Strategy, (DH 2009a) to deliver high quality care. These include: -

- Keeping people with dementia and their carers at the centre of developments through engagement with them about the support and services they require.
- Putting systems and services in place to ensure people with dementia and their carers retain control and choice over their lives and that the focus is on the individual's abilities.
- Ensuring general hospital staff is included in workforce development plans.
- Integrating volunteers into training and education opportunities where appropriate.
- Working with the local workforce to understand the most effective methods for delivering training and education.
- Maximising the potential for the joint commissioning of training and education programmes.

The Operating Framework for 2009/10 for the NHS in England High Quality Care for All, (DH 2008 p:23) has defined 'quality' in relation to care as: -

- Safety- ensuring that the environment is safe and clean
- Effectiveness- clinical outcomes and effectiveness of care from a patient perspective
- Patient experience- quality of care and the delivery of personalized care that focuses on compassion, dignity and respect

At a local level Somerset Health and Social Care Community comprising NHS Somerset, Somerset County Council, Somerset Partnership NHS Foundation Trust, Somerset Community Health, Taunton and Somerset NHS Foundation Trust, Yeovil District Hospital

NHS Foundation Trust, Care Focus Somerset and the Somerset branch of the Alzheimer's Society have responded to the aims set out in the National Dementia Strategy and High Quality Care for All by contributing to the development of, the Somerset Dementia Strategy (2010) which sets out the vision for services for dementia in Somerset. The Somerset Dementia Strategy (2010) provides a framework to deliver quality improvements to dementia services by addressing health inequalities relating to dementia and ensuring delivery on key ambitions and performance indicators. A key part of the Strategy is to 'raise awareness in both acute and community hospital settings' (p:22), in order that people with dementia and their carers have an improved experience resulting in improved health outcomes and quality of life.

As part of its aim to improve hospital care for people with dementia and to support the achievement of NHS Somerset strategic objectives the SSIF (Strategic Service Improvement Fund) Dementia Project, a multi-agency initiative was set up to focus on dementia training in order to develop the skills and knowledge of staff to enable better and more effective working with people with dementia and their carers.

SSIF Dementia Project Group

The SSIF Dementia Project Group agreed to move away from traditional models of learning and achieving change by being innovative in its approach to the project. As one member of the group highlighted: -

‘we’ve done lots of thing around dementia but we don’t fundamentally seem to have necessarily directly improved practice or awareness, so that’s why we went for a very different approach of employing practitioners, rather than spending money on a formal education programme, which doesn’t seem to have sort of influenced the care.... or the awareness’

Together with Bournemouth University the group worked to develop a programme for staff that would support them to work with dementia patients, families and their carers by: -

- providing practical learning and support
- working with them to develop practice
- providing sustainable learning opportunities

To achieve these aims a multi-agency Dementia Collaborative was set up led by a steering group that included senior representatives from healthcare providers in Somerset and Bournemouth University.

Steering Group –Role in Project

A Steering Group was established to develop and monitor work-plans, review the progress of the project and provide support to the project facilitators. The group was led and owned by the Acute and Community Trusts and supported by the Somerset Partnership. The Steering Group was comprised of senior and relevant members of staff from the Somerset Partnership, NHS Somerset, Somerset Community Health, Taunton and Somerset Trust, Yeovil District Foundation Trust, Bournemouth University and the Alzheimer’s Society.

Steering Group Terms of Reference and Aims

To ensure the SSIF initiative achieves its aims of developing skills and knowledge of staff in the Somerset Community to enable better and more effective working with people with dementia and their carers.

To ensure the project provides sustainable learning opportunities to deliver long term improvements for people with dementia and their carers by developing staff skills and knowledge.

To support and advise the Project Manager(s) to: -

- deliver the development of networks, materials and programmes
- set up and support a Somerset Dementia Collaborative – network for good practice, influencing change developing programmes, for the support of families and carers.

To ensure that staff in the health and social care community influence the delivery of the project so that it meets needs.

To ensure that carers / users views are included in the delivery of the project.

Aims

- To improve the experience of people with dementia and their carers when they are admitted to a general hospital or to a community hospital
- To develop staff skills
- To raise awareness of dementia
- To create a sustainable network for learning
- To work in partnership with Bournemouth University to: -
 - formally evaluate the project
 - give the project robustness and credibility
 - underpin the project with research evidence

Rationale for Evaluating the Project

The Steering Group's rationale for evaluating the project was to determine whether the innovative approach they had taken proved to be an effective method of learning and achieving change. Because as one member of the group commented: -

'what we are poor at doing is evaluating the effectiveness of projects..... and that was the purpose of doing it this way in a sense.....because we've been throwing resources at dementia and trying to change it, and people's perceptions and we are still trying to do it.....it was quite important for me to have some level of understanding about whether or not this type of methodology worked , um rather than you know some of the others which frankly, I am sure they have not worked because if they had we wouldn't have to keep going back to it'

The Steering Group recruited two members of staff to facilitate the project, on a part-time basis for one year with the overall aspiration to deliver an effective project that makes sustainable improvements in the skills and knowledge of staff in the Somerset Community, to enable better and more effective services for people with dementia and their families.

Description of Project Sites

Somerset is a rural county in the South West of England, with thirteen community hospitals and two general hospitals spread across 1,332 square miles. The map below indicates the location of the Community Hospitals. The District General Hospitals are located in Yeovil and Musgrove Park, Taunton

Map of Somerset showing the location of the Community Hospitals



Implementation of the Project

The two members of staff who were recruited to lead the project were selected because of their experience of working with patients with dementia and for their passion to improve dementia care.

They were aware of the time limitations of the project and the challenge posed by the geographical spread of the hospital locations within Somerset, and were 'mindful that by covering so many hospitals' that their input 'might be so diluted it may have not have been meaningful'. So the challenge for them was to devise an initiative that would be meaningful for staff working with patients with dementia and that would support them to deliver care based on the humanisation framework, (Todres *et al* 2009), an approach being developed and pioneered by three academics at Bournemouth University. Their aims were to change people's perspective of and, attitudes to dementia patients by creating an awareness of what it might be like to be a patient with dementia on a hospital ward.

To achieve their aims the two project leads (project facilitators) took a three-pronged approach and devised: -

- Lived Experience Workshops an hour long awareness raising session designed to engage with as many staff as possible
- Ward-based projects to engage with staff at a practice level
- An online sustainable network on Huddle.net

Humanisation Framework

The project facilitators utilised the eight dimensions of 'The humanisation of healthcare: A value framework for qualitative research' (Todres *et al* 2009) to partially devise both the Lived Experience Workshops and the ward-based projects. To assist the reader and highlight the importance of this framework for its practice ability to humanise dementia care we would like to locate this framework within earlier and emerging themes in dementia care.

A great deal of work has been done by researchers and clinicians to identify and describe the symptoms of memory loss, but these technological accounts of illness remain abstracted from the meaningful context of lived experience, (Cash 2009). Kitwood challenged this medical model of dementia in his development of 'person-centred care' where he defined 'personhood' as "a standing or a status that is bestowed on one human being, by another in the context of relationship and social being" (Kitwood, 1997). This 'placed the person [with dementia] first' and supported practices, which enhanced their wellbeing and dignity.

Person-centred care has not been without its critics. An important area of critique argues that seeing personhood as something bestowed on people with dementia undermines recognition that people with dementia have agency (Adams, 2005) and positions the person with dementia as passively dependent (Bartlett and O'Connor, 2010).

The term humanisation of care has been increasingly used to describe an approach to health and social care that is centrally informed by core dimensions of what it means to be human. The humanising framework proposed by Todres *et al* (2009) from Bournemouth University provides eight bipolar constructs, each of which communicates both the humanising and dehumanising features of care and its context. The following table names the eight dimensions of humanisation together with their polar opposites (dehumanising dimensions) in each case. The table is presented in order to help the reader imagine each dimension along a spectrum of possibility rather than implying either/or extremes.

Table I. Conceptual framework of the dimensions of humanisation.

Forms of Humanisation	Forms of Dehumanisation
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenisation
Togetherness	Isolation
Sense making	Loss of Meaning
Personal Journey	Loss of Personal Journey
Sense of Place	Dislocation
Embodiment	Reductionist Body

These eight dimensions articulate core features of what needs to be attended to in order for a person to feel more deeply ‘met’ as a human being.

1.Insiderness and Objectification

Objectification has been defined as the dehumanisation of patients resulting from focusing on how patients fit into a diagnostic system that labels them and does not take account of their insiderness, (Todres *et al* 2009). The act of ‘dehumanising’ patients with dementia has an adverse effect on the interactions between staff and patients with dementia.

2.Agency and Passivity

The ability to make one's own decisions is key to personal freedom and agency. In the provision of care to patients with dementia, individual choice is often taken away on the premise that they are unable to make choices. While this may be true for patients in the later stages of dementia it should not be assumed that all patients with dementia are unable to exercise agency in some aspects of their care.

3.Uniqueness and Homogenization

Treating patients with dementia as a homogenous group, fails to recognize uniqueness or individuality. Becoming aware of a patients' individuality supports staff to deliver a more humanized form of care that is responsive to individual needs.

4.Togetherness and Isolation

For patients with dementia, when their everyday social connections are disrupted, they can feel a sense of isolation, loneliness and alienation from others. This can be exacerbated by institutionalized healthcare systems and practices.

5.Sense making and Loss of Meaning

Patients with dementia are often confused and unable to make sense of their surroundings and why they are there. This often results in them putting up resistance to caring tasks, as they do not understand what they are being asked to do. Supporting them to make sense of their situation and surroundings by increasing their understanding of processes, rather than simply carrying out tasks without explanation, can impact positively on the patient and make providing care easier.

6.Personal Journey and Loss of Personal Journey

Loss of personal journey can happen when healthcare practices do not take account of the history and possible future of a person's life. Patients with dementia may need the support

of others to tell their life history. The feeling of knowing who they are helps patients with dementia know and feel how their care is linked to their history.

7.Sense of Place and Dislocation

Unfamiliar surroundings and routines can cause considerable stress in patients with dementia. Supporting them to feel comfortable in the hospital surrounding can lead to significant improvements in their quality of life.

8.Embodiment and Reductionist Body

A reductionist view of the body reduces the patient with dementia to a collection of signs and symptoms. An approach to their well-being includes ways to connect to their interests and connections beyond their illness.

These eight dimensions of the humanising framework were used to underpin learning for both the Lived Experience Workshops and the Ward projects by applying them to examples of practice.

Lived Experience Workshops

The project facilitators designed the workshop sessions to support staff to see the patient with dementia as a person rather than a 'diagnosis' in order to allow them to deliver personalised care based on the principles of the humanisation framework, (Todres *et al* 2009).

The sessions began with a visualisation exercise outlined by Brooker & Surr (2005). During this exercise participants were encouraged to consider the sights, sounds, feelings and frustrations, which could be experienced by a patient with dementia who was resident on their ward. After the exercise the project facilitators gave the participants time to explore their feelings and discuss possible solutions. Two scenarios relating to two imaginary

patients named 'Doug' and 'Rose', where staff was asked to consider the challenges that patients with dementia might face when coming onto their ward *rather* than the challenges the staff themselves might face, followed the visualisation exercise.

The project facilitators commented on the positive outcome of using the visualisation exercise as a learning exercise, for its ability to engage staff in the learning process in a different way to more traditional forms of learning: -

'Y'know they were perhaps expecting us to impart some knowledge to them, whereas that really wasn't what it was all about'.

Engaging staff in this way invited them to step 'out of their comfort zone' into the world of the patient with dementia and allowed them to experience and reflect on the challenges facing patients with dementia in a busy ward environment. As one of the project facilitators commented,

'people actually became that person suffering from dementia for a short time, so that was an achievement'.

The scenarios based around 'Doug' and 'Rose' placed a 'different emphasis' on understanding by focusing on the patient experience rather than the staff experience. It asked staff to consider what difficulties a patient with dementia might experience as part of the 'ward regime'. This encouraged staff to look for their own solutions to the problems facing a patient with dementia on a hospital ward.

The facilitators provided a supportive environment for staff to consider both their current and future practice, based on their learning from the workshops. As one of the facilitators commented: -

‘I was keen not to just leave people feeling raw, but to offer some way forward as well, because I think that is really important..... on the whole it was positive and it worked on an emotional rather than an intellectual level and for that reason it touched people a bit more and that was how the feedback came across’.

Ward Based Projects

In order to engage on a practice level with ward staff the project facilitators devised a number of ward-based projects. The themes for the ward-based projects were chosen by the project facilitators based on, ‘their recurring appearance in both Department of Health and Alzheimer’s Society publications’. They identified six themes from the literature: - Nutrition, Use of Anti-Psychotic Medication, Environment, Occupation, Person Centred Care and Involving Carers. Within the time scale of the project their aim was to work closely with small groups of staff to achieve ‘something tangible and something that conceivably could be rolled out’. The project facilitators compiled a folder for each of the topics containing key research relating to the topic theme. When compiling the folders they were keen to make the information as concise and informative as possible as they were aware that staff, ‘don’t just have time to sit and read through things’.

In liaison with the hospital dementia leads, ward sisters/managers were invited to take part in a ward-based project, to select the theme they wanted to explore and to decide who would become involved in the project, with the only stipulation being that all levels of staff should be given the opportunity to participate. As such the numbers of staff participating in individual projects ranged from two to seven people. Eleven wards chose to participate in a ward-based project, within the time-scale of the project. None of the wards participating in the project chose to undertake projects in the topic areas of nutrition and the use of anti-psychotic medication. Three wards undertook projects relating to their ward environment and its ability to support patients with dementia. Three wards undertook projects relating to occupational activities for patients with dementia. Two wards undertook projects looking

at person-centred care. Three wards undertook projects involving carers of patients with dementia.

In order to accommodate staff pressures and ward routines the facilitators arranged the project sessions to take place at handover periods. The introductory session took place on the ward with a cross section of staff. At the initial session the project facilitators outlined key research associated with each of the themes. They then used the humanising framework as a basis for discussion with the staff using prompts such as: - how do you make sure that patients with dementia have a say in their care? The sessions were designed to build upon existing staff expertise. This was based on the understanding that their knowledge of their own wards made any interventions or changes more likely to be successful. Each ward was invited to draw up an action plan and these were then reviewed with the ward staff and the project facilitators over the succeeding months. (See Appendix 1 for an example of a ward action plan).

A carer who had experience of both General and Community hospitals was present and contributed to some of the introductory sessions. She was able to bring a carers perspective to the session. She saw her role as: -

‘putting the human face on the carer, who then puts the human face on the patient’.

Speaking from personal experience she was able to highlight the importance of involving the carer as ‘an asset and not as a pain in the butt’, not only for their ability to give staff a history of the patient with dementia but also for their ability to provide support in caring for the patient with dementia.

In addition the ‘This is me’ booklet produced by the Alzheimer’s Society was introduced to each of the participating wards. This is a simple and practical tool that provides a 'snapshot' of the person with dementia, giving information about them as an individual, such as needs,

preferences, likes, dislikes and interests, enabling staff to see and treat each person as an individual. The use of the booklet was also responsible for 'initiating' discussion with carers about their loved one and as one of the project facilitators commented, 'that means their dialogue is on a better footing right from the outside'.

Because of time implications it was key that each group of staff took 'ownership' of their project and responsibility for working towards the goals they set in their action plan. The project facilitators highlighted that what the project had: -

'allowed them (staff) to do, and the hierarchy have allowed them to do, is initiate change and to take control of things themselves That's quite a big achievement because I think a lot of the time the people on the ward know what works and what can help.....people had all these ideas but they'd never done anything about it. And the fact that their organisation had put us in gave them permission to try and do stuff'.

Huddle Network

In order to provide sustainability after the project end in collaboration with colleagues from the Strategic Health Authority in Somerset the project facilitators, developed an online resource through Huddle.net. This was designed to allow practitioners to share information and ideas across the geographically disparate area.

The Somerset Collaborative for Dementia Care Workspace is accessed by invitation only. Invited members include: the steering group, Dementia Champions/Leads from hospitals within Somerset, staff involved in ward-based projects and staff from Bournemouth University.

The workspace is comprised of three areas: -

4. Files containing national papers, policy documents, training opportunities and individual folders relating to ward-based projects
5. Discussion Forum, where members of the group are encouraged to post topics for discussion relating to dementia care
6. A whiteboard for members to post events relating to dementia care

Approach to the Evaluation

The project has been evaluated through a mixed range of data sources including interviews, questionnaires, post-it-note feedback, policy documents, minutes from steering group meetings and ward action plans. As this was a service evaluation there was no need for formal ethics approval, however the project team were careful to adhere to appropriate research ethical guidelines of anonymity, beneficence and informed consent.

Interviews

Interviews were carried out with the aim of gleaning experiences from a range of people participating at different levels in the project. The interview participants were a self-selecting purposive sample. Holloway and Wheeler (2010 p:146) caution that in qualitative research 'a large sample is unnecessary and might result in less depth and richness' of data being obtained. Thirteen people with a range of involvement in the project gave consent to be interviewed. Interviews were conducted with four members of the Steering Group. These interviews took place by telephone because of the geographical spread of the participants. Six members of staff involved in ward projects elected to be interviewed about their experience of engaging with the project. The interviews took place within the work setting with the exception of one, which took place in the participants' home. The two members of staff leading the project were interviewed about their experiences of leading the project; they elected to be interviewed at the university. A carer who was involved in the project for their ability to give a carer's perspective was interviewed about their participation in the project and elected to be interviewed at their home address.

Interviews lasted between twenty minutes and one hour. The interviews contained a series of pre-planned open questions designed to gather rich descriptive data about the participant's experience of participating in the project. The sequencing of questions was dependent on the process of the interview and the responses of each individual. This

approach to interviewing ensures that similar types of data are collected from all participants (Holloway & Wheeler 2010). Probes were used to explore relevant issues. The specific questions used for each group of participants (i.e. steering group members, staff participating in ward projects, the carer and the project leaders) were designed to reflect their individual roles in the project. The rationale for the interviews was to encourage participants to share their experiences of engaging in the project, their expectations for the project, and the learning that they had gained from their participation.

The interviews were recorded with the consent of the participants, transcribed and analysed using thematic analysis.

Self-Completion Questionnaires

To obtain feedback about the value of the initiative for enhancing the professional development of staff, the project facilitators together with staff from Bournemouth University designed a self-completion questionnaire framed around the eight humanising dimensions of healthcare proposed by Todres *et al* (2009). For the purpose of the questionnaire, the humanising dimensions were related to practice in the following way; through engagement with the project: -

Agency: 'I have become more confident that I can help people with dementia have more say, in their care in an everyday way'.

Sense of Place: 'I have become more confident that I can make people with dementia to feel more at home in the places that they receive care'.

Sense of journey: 'I have become more confident that my care and treatment of a person with dementia takes into account their life history as well as what has gone before in their care'.

Togetherness: 'I have become more confident that I can help people with dementia feel more connected to the people that matter to them and their lives outside healthcare'.

Uniqueness: 'I have become more confident that I can help people with dementia feel that their specific and individual needs are being addressed'.

Sensemaking: 'I have become more aware of the kind of information it is important to give people with dementia so that their treatment makes sense to them'.

Embodiment: 'I have become more confident that I can enable people with dementia to feel that their care is directed to their life and well-being and not just to the alleviation of symptoms'.

Insiderness: 'I have become more confident that I am able to see things from the perspective of the person living with dementia and am able to respond more empathically on the basis of this understanding'.

In addition to these eight questions, staff participating in ward projects, were asked to respond to additional questions relating to the specific ward project they were involved with. (See Appendix 2 for details of the questions)

Participants were asked to respond to the statements by circling their response on a five-point scale ranging from Strongly Agree to Strongly Disagree.

Lived Experience Workshops Evaluation Questionnaires

A total of one hundred and three questionnaires were distributed to participants attending Lived Experience Workshops. Fifty-four completed questionnaires were returned, giving a response rate of just over fifty per cent. Data from the questionnaires was analysed using SPSS 16 (Statistical Package for Social Sciences).

Ward Projects Evaluation Questionnaires

The project facilitators distributed evaluation questionnaires to members of staff participating in ward projects, when individual projects reached their review stage. Nine out

of the eleven ward projects reached their review stage within the timescale of the project. A total of 39 questionnaires were distributed for completion and over a third of these were returned for analysis. Data from the questionnaires was analysed using SPSS 16 (Statistical Package for Social Sciences).

‘Post-it-Note Feedback’ from Lived Experience Workshops

Lived Experience workshops took place at eleven hospitals, within the project area. A total number of 139 staff from across the county attended a workshop. The staff attending the workshops included junior and senior members of the nursing staff, and other allied health professionals.

At the end of each session feedback was collected from participants. Workshop participants were asked to leave written comments on post-it-notes in response to the following statements: -

- A message to the facilitators
- What area of good practice will you either continue or begin following this session?

Comments from the Post-It-Notes were collated and analysed using thematic analysis.

Evaluation

Lived Experience Workshops

‘Post-it-Note Feedback’

Staff attending the workshops reported finding them informative and thought provoking and commented on how they had increased their awareness by allowing them to consider the perspective of the person with dementia and understand how ‘a patient with dementia might feel’ in a strange environment. The following quotes illustrate the understandings that were gained: -

‘It makes me understand what a lonely world patients (with dementia) live in’

‘Allowed me to understand how a patient may feel’

This understanding of ‘the world’ of the person with dementia was enhanced by the visualisation exercise, which workshop participants found valuable for its ability to allow them to ‘see the world from a dementia person’s eyes’: -

‘this was a different approach, closing eyes and imagining’

‘the exercise was valuable in reminding us to value’

This interactive approach to learning allowed participants to visualize the world of a person with dementia and in doing so allowed them to ‘take a walk in another person’s shoes’, allowing them to gain an empathic understanding of the world of the patient with dementia.

As a result of attending the session participants indicated that they would continue or begin following these areas of good practice: -

Communication

Staff recognized the importance of initiating effective communication with both the patient with dementia and their carers and family relatives. In order to support this process the hospitals participating in the project have adopted the use of the “This is me” booklet produced by the Alzheimer’s Society. It provides a 'snapshot' of the person with dementia, giving information about them as an individual, such as needs, preferences, likes, dislikes and interests. This information should enable staff to see and treat the person as an individual rather than a ‘diagnosis’ thereby reducing distress for them and their carers. In their feedback staff highlighted the need to: -

- Spend more time communicating effectively with patients
- Communicate with carers and families to build a history of the patient
- Talk to person, find out more about them if you can, don’t just see as a patient
- Listen and validate the individual, making them feel safe and understanding of their situation

Time

Staff experienced the world in a ‘different time-frame’ during the visualisation exercise; they saw professionals as ‘moving really quickly’ and ‘just whizzing past’. They likened the experience to ‘time lapse photography’ where things appear to have been speeded up. They acknowledged that they needed to, ‘give patients more time, not to be in such a rush’. As a result of this in their feedback comments they said they would: -

- Give a patient more time to try and gain information on their own routine, likes, dislikes and to make them feel more settled in their unknown environment
- Reassure patients more often as to what is going on

- Try and change my practice to put myself into these patients' shoes and accommodate them more

Humanising Practice

Using these strategies to gain greater insight into the world of the patient with dementia, allowed staff to think about ways they could 'enhance their practice'. In particular they found it helped them to see the person *behind their diagnosis* of dementia, 'it was good to be reminded about looking at a person holistically'. As a result staff said that they would 'give patients more of their time' and engage with them by chatting, smiling, and reassuring them through touch. In their feedback comments, staff said they would: -

- Listen and 'validate' the individual making them feel safe
- Recognize the patients loss of independence and empowerment
- To think about how a patient might feel and make things easier for them
- Considering patients personal history/life experiences more
- Need to speak and interact so (the) patient is not left feeling isolated

Training

Staff welcomed the opportunity to engage in the Living Experience Workshops but indicated that they would like further training and information on how to 'reassure and comfort patients with advanced dementia' and in particular in dealing with what they termed 'challenging behaviour'. This request for more training was highlighted by one of the project facilitators: -

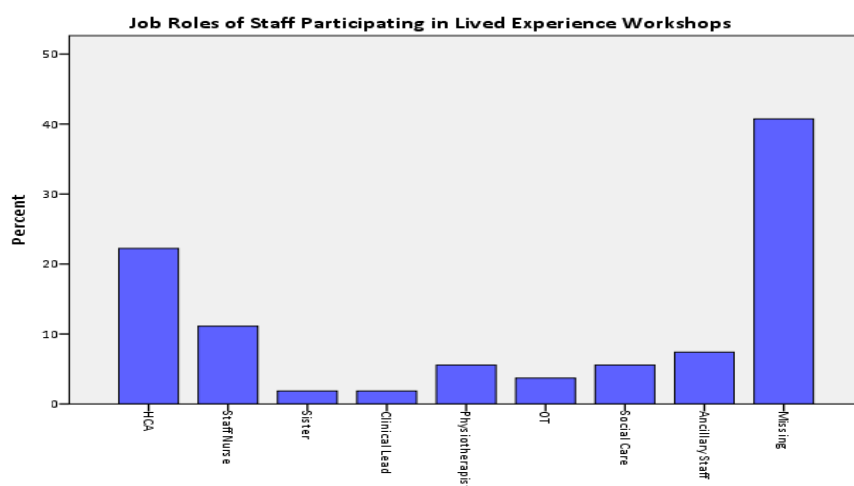
'Really most of the staff that we worked with, are crying out for more training, more understanding'.

Results from Lived Experience Workshops Questionnaires

Profile of staff attending Lived Experience Workshops

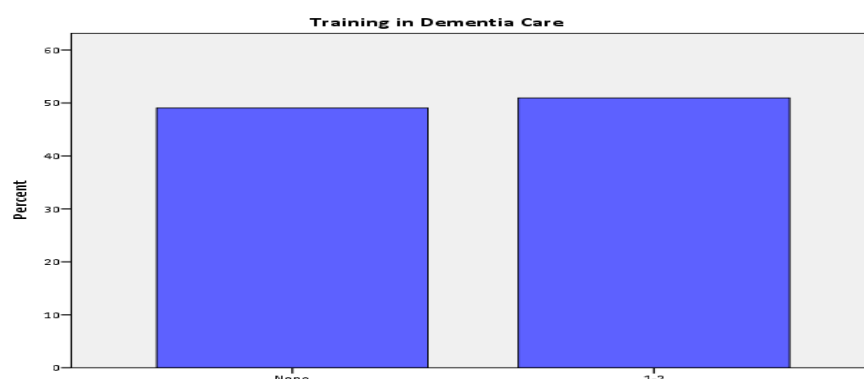
With the exception of one male all of the staff attending a Lived Experience Workshop were female. Six per cent of the staff were aged between 18-24 years, four per cent of the staff were aged between 25-30 years, four per cent were aged between 31-35 years, six per cent were aged between thirty six and forty years, twelve per cent were aged between 41-45 years, sixteen per cent were aged between 46-50 years, twenty-two per cent were aged between 51-55 years, and 29 per cent were aged over fifty-six years. Fifty-seven per cent of staff worked full-time and forty-three per cent worked part-time. Thirty-nine per cent of the staff had up to ten years experience, twenty-four per cent had between 11 and 20 years experience, and thirty- five per cent had over 21years experience.

Graph 1: Range of Job Roles of Staff Participating in Lived Experience Workshop.



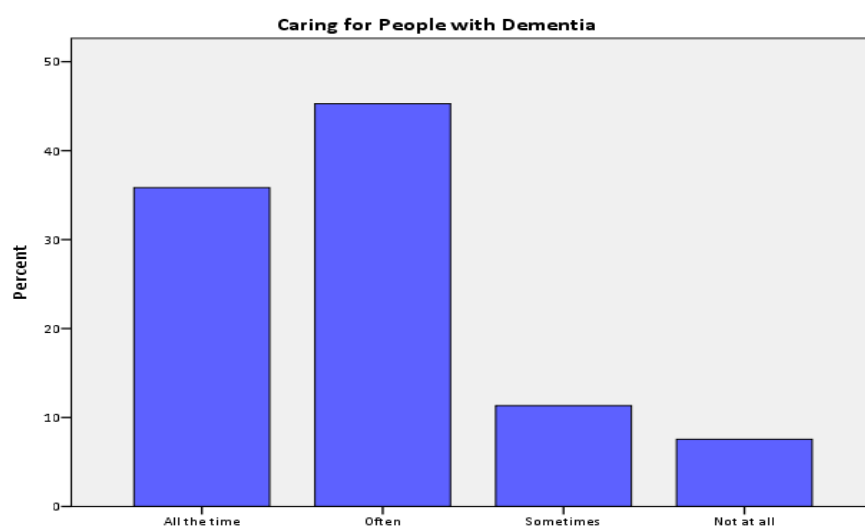
Staff from a wide range of occupations and roles participated in the Lived Experience Workshops.

Graph 2: Staff who have attended a Course or Training in Dementia Care in the Past Two Years.



Forty-nine per cent of staff had not previously attended a course or training in dementia care in the past two years, fifty-one per cent had attended up to two courses.

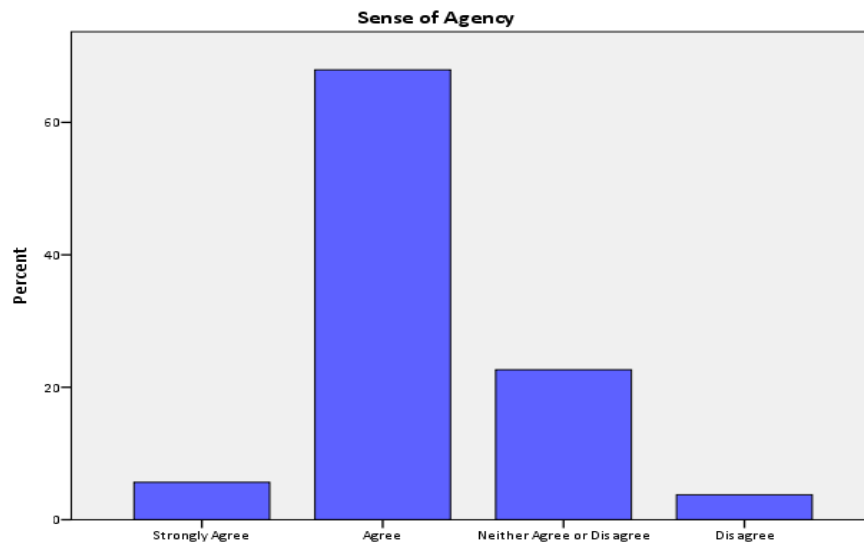
Graph 3: How often have you cared for people with dementia in the last year?



Thirty-six per cent of the staff said they cared for people with dementia all of the time, forty-five per cent said they often care for people with dementia, eleven per cent said they sometimes care for people with dementia, and eight per cent were not involved in caring for people with dementia.

Graph 4: Agency

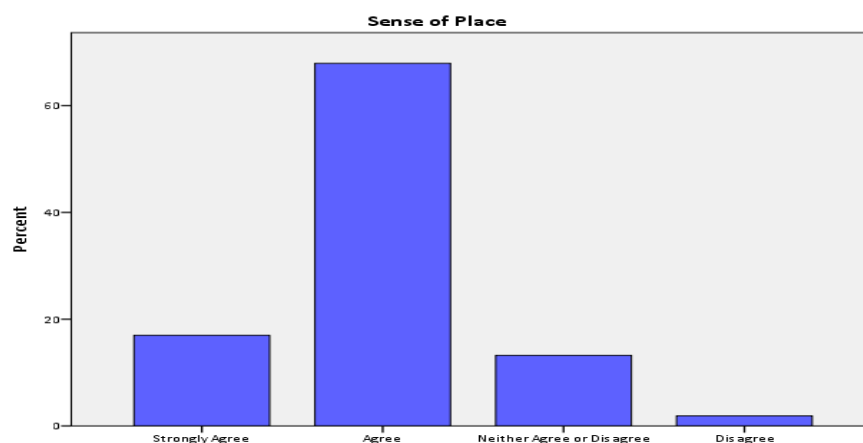
Through engagement with the project I have become more confident I can help people with dementia have more say in their care in an everyday way.



Seventy four per cent of the staff that answered this question agreed, or strongly agreed that they felt able to support people with dementia to have more say in their care.

Graph 5: Sense of Place

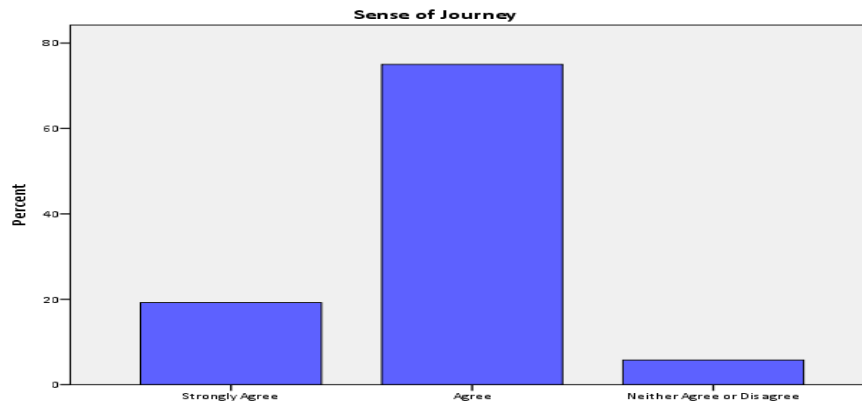
Through engagement with the project I have become more confident I can make people with dementia to feel more at home in the places that they receive care.



Eighty five per cent of the staff that answered this question agreed, or strongly agreed that they felt able to make people with dementia feel at home in the place they received care.

Graph 6: Sense of Journey

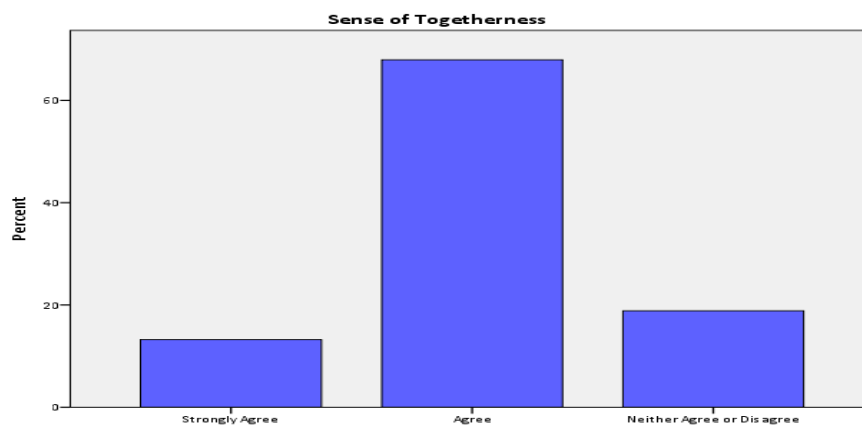
Through engagement with the project I have become more confident my care and treatment of a person with dementia takes into account their life history as well as what has gone before in their care.



Ninety four per cent of the staff that answered this question agreed, or strongly agreed that they would base their care on the life history of the person with dementia.

Graph 7: Togetherness

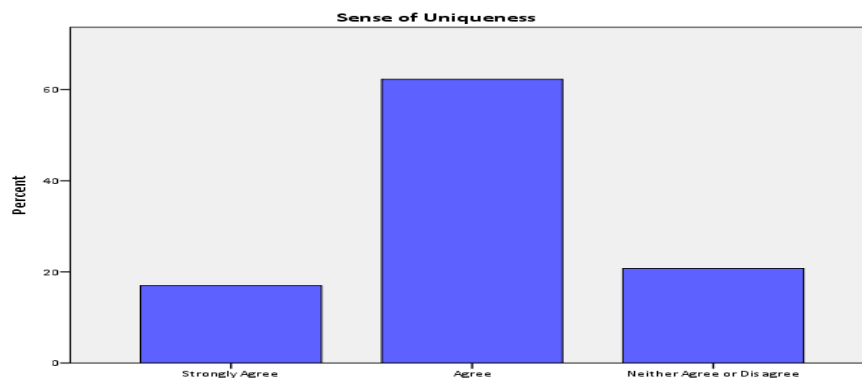
Through engagement with the project I have become more confident I can help people with dementia feel more connected to people that matter to them and their lives outside healthcare.



Eighty one per cent of the staff that answered this question agreed, or strongly agreed that they could help people with dementia feel more connected to people that were important to their lives outside of healthcare.

Graph 8: Uniqueness

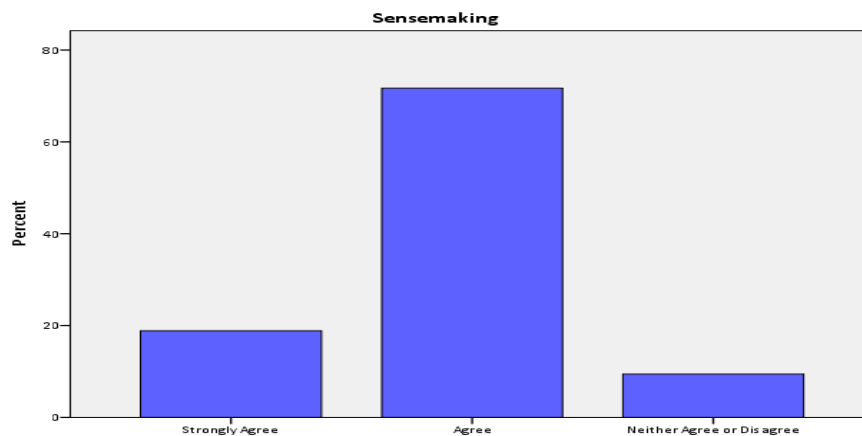
Through engagement with the project I have become more confident I can help people with dementia feel that their specific and individual needs are being addressed.



Seventy nine per cent of the staff that answered this question felt that they could help people with dementia to feel that their specific needs were being addressed.

Graph 9: Sensemaking

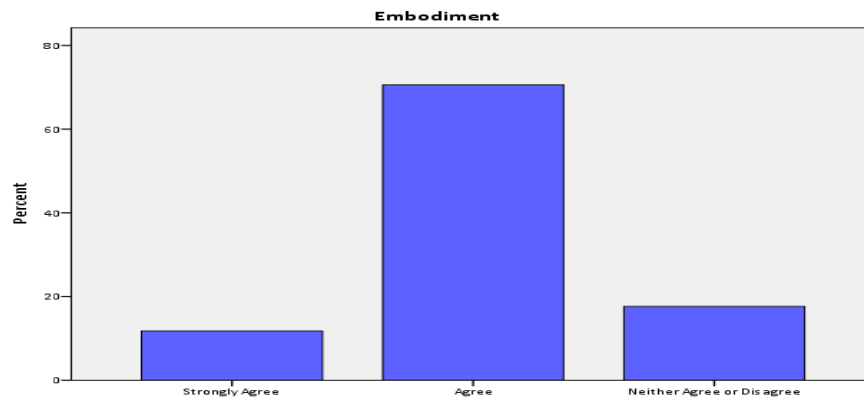
Through engagement with the project I have become more confident I have become more aware of the kind of information it is important to give people with dementia so that their treatment makes sense to them.



Ninety one per cent of the staff that answered this question felt that they were more aware of the information that people with dementia needed to be given to enable them to make sense of the treatment they were being given.

Graph 10: Embodiment

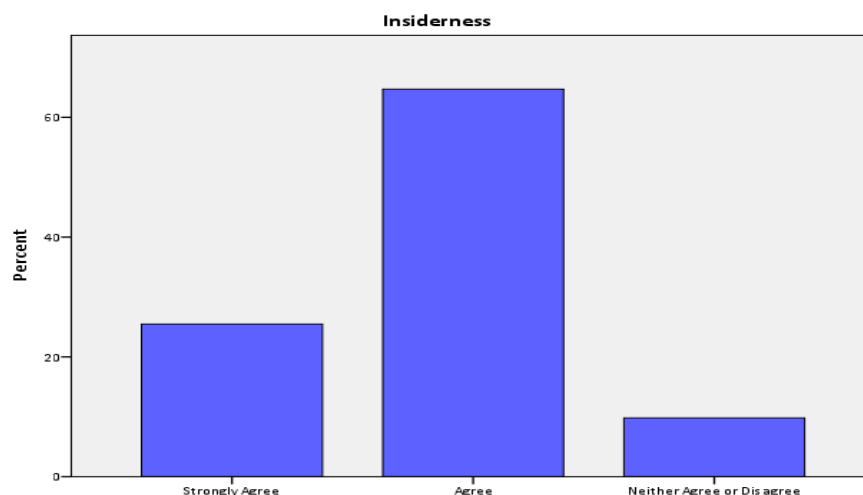
Through engagement with the project I have become more confident I can enable people with dementia to feel that their care is directed to their life and well-being and not just to the alleviation of symptoms.



Eighty three per cent of the staff that answered this question felt that they could enable people with dementia to feel that their care is directed to their well-being and not just to the alleviation of their symptoms.

Graph 11: Insideriness

Through engagement with the project I have become more confident I am able to see things from the perspective of the person living with dementia and am able to respond more empathically on the basis of this understanding.



Ninety per cent of staff of the staff that answered this question felt that they were able to see things from the perspective of the person with dementia and respond more empathically to them.

Ward-Based Projects

The following narrative presents the learning experiences of staff that became involved in a ward-based project. All identifying features have been anonymised throughout in terms of participating individuals and settings.

Ownership

Staff reported that the traditional methods of achieving change in hospitals normally tend to be 'top down' and involve meeting specified targets, for instance: -

"we are very target driven. Everything is made and measured and everything is how many of this have you got, and how many of that, and can you evidence that, and where's your signing sheets for this and your table for that and your spreadsheets'

Initially when they engaged with the project, staff found it difficult not having defined boundaries and set goals. However with the support of the two healthcare professionals facilitating the project staff took 'ownership' of the ward-based projects and produced action plans for change that were responsive to the challenges on their own particular wards, as the following quote illustrates: -

"what's positive about it is they've the team have come up with what they wanted to do and they've initiated it and they've done it and they've seen the results and I think that helps to bridge that theory/practice gap.....because it's practical and it's really based on the work place and doing things with patients in your own place of work ".

Staff were positive about being supported to achieve change in a way that was responsive to their own ward environment rather than on having to achieve goals and targets imposed on them from outside, as one member of staff acknowledged: -

“we know the personalities in our team..... who we are going to get resistance from and how to counteract that resistance.....somebody coming in doesn’t have all that insight do they?we can do the activities to suit the environment, the patient and us”.

Achieving change using this model of involvement was seen as more effective than traditional methods of classroom based teaching that take place outside of the ward environment: -

“because if you are just going away and learning about dementia and they say ‘go back to your area and implement something’ people come back and get busytied up with their work and they don’t necessarily ever initiate anything’.

Better communication with carers and family members

Engaging with carers and family members at the earliest opportunity aids communication between hospital staff, because it has the ability to, in the words of one interviewee: -

“put(s) the human face on the carer, who then puts the human face on the patient”

This supports the staff to see the person behind the diagnosis of dementia, and also leads to more effective communication and better relationships with carers and family members. In addition, the use of the ‘This is me’ booklet has enabled staff to give more personalized care based on the patient’s history. It has also helped staff to interpret what they might previously have regarded as ‘challenging behaviour’, such as the patient walking around the ward, because they are able to use the knowledge gained from the patients history to understand that this is part of their normal daily routine when they are at home: -

“well it’s probably better for them to walk around and that because that’s what they do at home, don’t they?’We do let them get up and walk ...”

The ‘little things’ we have changed

The changes that occurred on wards were often referred to as ‘little things’ or ‘small changes’, such as: -

“there are small things that we could do that could make a big difference ...we don’t have to re-design the whole service or anything. It’s achievable”

The changes that have been achieved have started to have a positive impact on the patient experience, for example: -

“I think that we are more sensitive to them and to their needs and to the environment”.

Preparing action plans for their chosen project encouraged staff to ‘look more globally’ at the ward environment, as illustrated in one interviewee’s words: -

‘We’re not just looking at occupationwe need to go much broader....all the other projects that were available really because they are all just as important’.

This often resulted in them making changes in areas outside of the specific project they had chosen to implement. For instance, one ward that was looking at occupation also found

themselves looking at the ward environment and as a result, re-located their dining area to give patients more space, as illustrated below: -

“we were getting more people up for lunch.... they really enjoyed the interaction, no matter what stage of cognitive impairment...they seemed to enjoy sitting round a table talking to everyone else”.

Engaging with patients with dementia

The project has supported staff to engage with patients with dementia by enabling them to become ‘more sensitive to them (patients with dementia) and to their needs’: -

“there is a bit more understanding of well, y’know that we have to go into their world sometimes. Not try and force them out of it and into our world’.

It was acknowledged that staff who engage with patients with dementia need to develop supportive relationships based on understanding and prior knowledge of the patient’s life history as: -

“patients with dementia are much harder to look after if you don’t understand their circumstances, if you don’t understand their condition, if you don’t understand how best to care for them”.

Initiatives that have emerged from Ward-Based Projects

A number of innovative initiatives have emerged from the ward-based projects that support patients with dementia in ways that are highly consistent with the eight dimensions of the humanising framework, that we elaborate on in the body of the text: -

- **Picture Menus:**
Used to inform patient's choice of meal, and enable them to exercise agency.

- **Memory Boxes**
Used to stimulate patients to recall past events and support them to engage in conversation and make sense of things.

- **Tea Parties**
Used to promote social interactions and provide cues for eating linked to past meaningful connections.

- **Coloured Crockery**
Used to alert staff that the patient might require support with eating and to support the perceptual abilities of the person.

- **Hand Massage**
Used as a form of relaxation therapy and as a way of connecting with patients as individuals in an embodied and person centred way.

- **Planting bulbs**
Used as a way of engaging patients in meaningful activity, and as a prompt for patients to recall past experiences from their life history to enhance their sense of place and sense of journey

- **Activity sessions**
Used to engage patients in a variety of meaningful activities that make meaningful connections for them.

- **Improved Signage**
Used to support patients with dementia to navigate the hospital environment.

- Adoption of the 'This is me' booklet
Used to provide staff with information about the patient, to enable them to see the person with dementia behind the diagnosis and to facilitate an individualised approach to care, enhancing insidership.
- A Communication Booklet
Developed to support staff to communicate with patients with dementia in ways that are sensitive to patients' unique history and needs. The booklet is now published and available to improve practice nationally.
- Volunteers reading to patients
Volunteers were recruited to read to patients to support meaningful occupation and to stimulate conversation to facilitate a sense of connection with others .
- 'Treasure boxes'
Boxes containing personal items that are significant to individual patients to support them to feel more secure in unfamiliar surroundings, provide staff with clues about the past history of the patient and, act as a medium for enabling meaningful communication, enhancing a sense of journey.

In addition dialogue, has also been opened up between the participating hospitals, and they are exchanging ideas of good practice that have evolved from the projects.

Barriers

The following were listed as barriers to the success of implementing ward projects: -

Time: Ward staffing pressures and the attendance at statutory training were identified as barriers to releasing staff to attend training non-mandatory training. Staff sometimes did not have time to engage with ward projects during their working hours but, as a result of their commitment to the projects they were involved with, they worked on them in their own time at home, and came in on their days off to engage in activities, for example: -

“I came in on my holiday, (-) came in on her holiday so y’know without that it wouldn’t have gone anywhere really”.

However it was also acknowledged that lack of time could also be used as an excuse to cover up staff reluctance to engage with people with dementia because: -

‘they don’t feel skilledpeople don’t feel they know enough or they don’t feel they’ve got the ability to do it’

Resources: Financial resources were not always available to support changes that projects would like to make particularly if structural changes were involved: -

“That was my stumbling block, that’s when I was talking about the changes that involved money”.

Structural Design: The structural design and ward layout of the individual hospitals proved to be barriers (e.g. toilets situated outside of bed areas, single bedded rooms and lack of space) which meant that staff were unable to initiate some of the changes they wanted to make to the environment to support patients with dementia. Staff acknowledged the constraints and tried to work around them: -

“It is trying to be sensible around the environment you work in.....years ago we did have day rooms and unfortunately they’ve gone to offices”

But in some instances they were unable to overcome the constraints. For example one ward wanted to encourage patients with dementia to eat by setting up an area where they could eat together but were constrained by lack of space: -

“I was going to get the tables. The difficulty is picking the right patients, knowing that other patients in that bay aren’t at risk of a sudden emergency because you couldn’t have a table in the bay and then there be an emergency situation”

Cross Department Working: Some projects encountered difficulties when they needed to involve other departments in changes they wanted to make, for example, hanging signage, changing the colour of bedding, putting up handrails and flexibility in meal provision. This resulted in delays to the changes being made for example: -

“we were looking for them to provide pictorial signs for our toilets and bathrooms. It’s on a list with our estates manager that’s not been done yet. It’s on my list, it’s on my action plan and I’ll continue to persevere’.

Staff Attitude: Concerns were raised that some staff were perceived to be more focused, on task centred care, than on seeing the person: -

“I think nurses are a bit more task-driven and task-orientated and we’ve got to stop that and we’ve got to bring it back to being more of a holistic approach and very person centred”

It was also reported that some staff regard dementia as a mental health issue and feel that patients with dementia should not be cared for on general wards: -

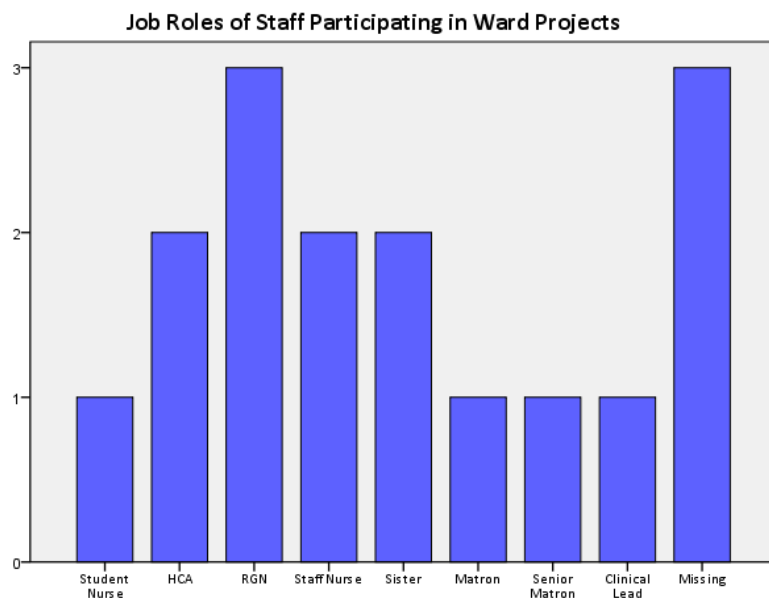
“this isn’t the right place for themthey shouldn’t be here this is for really sick people”

Results from Ward Project Questionnaires

Profile of staff participating in a Ward-Based Project.

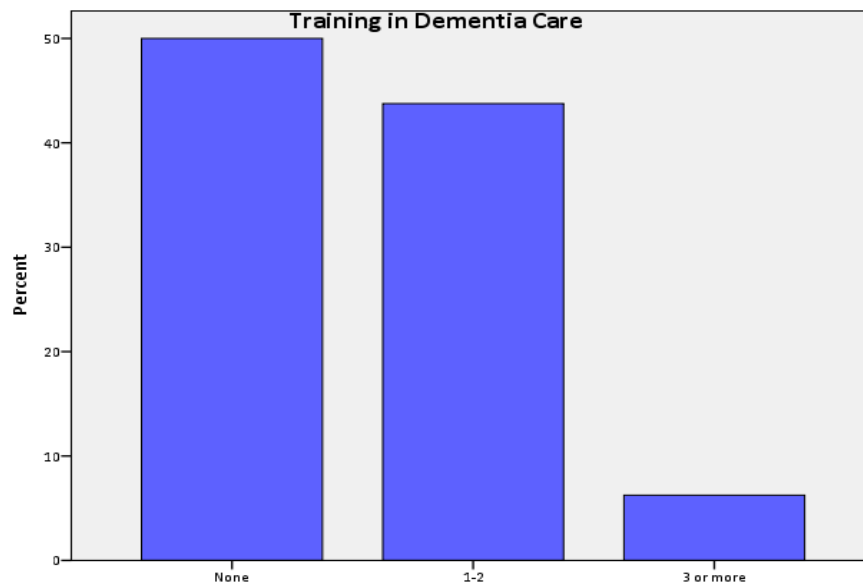
All of the staff participating in ward projects were female. Six per cent of the staff were aged between 25-30 years, six per cent were aged between 31-35 years, thirteen per cent were aged between 36-40 years, twenty five per cent were aged between 41-45 years, twenty five per cent were aged between 46-50 years and twenty five per cent were aged between 51-55 years. Seventy-five per cent of staff worked full-time and nineteen percent worked part-time, six per cent failed to say whether they worked full-time or part-time. Eighteen per cent of the staff had up to five years experience, twenty-five per cent had between 6 and 10 years experience, six per cent had between 16 and 20 years experience and fifty per cent had over 21years experience.

Graph 12: Range of Job Roles of Staff Participating in Ward Projects.



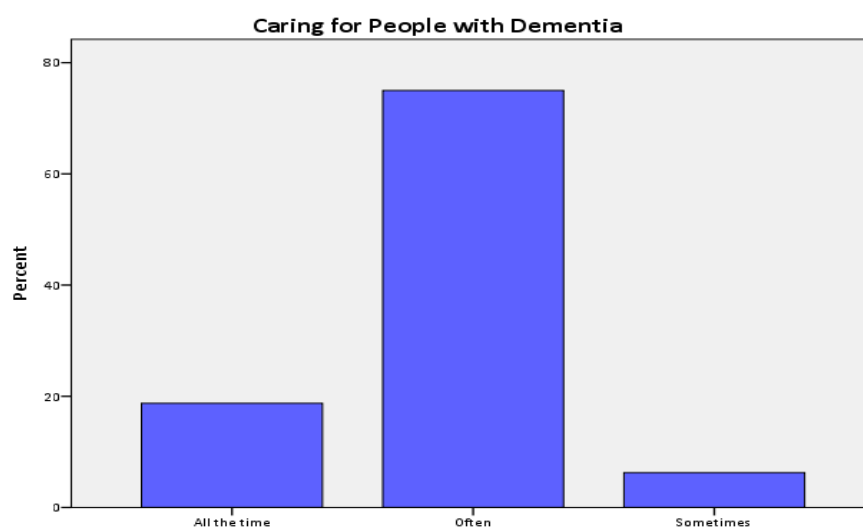
The roles of the staff who participated in ward projects, ranged from junior to senior positions.

Graph 13: Staff who had attended a Course or Training in Dementia Care in the Past Two Years.



Fifty per cent of the staff participating in a ward project had never attended a course or training in dementia care, forty four per cent said they had attended between 1 or 2 courses and 6 per cent said they had attended three or more courses or training in the last two years.

Graph 14: How often have you cared for people with dementia in the last year?

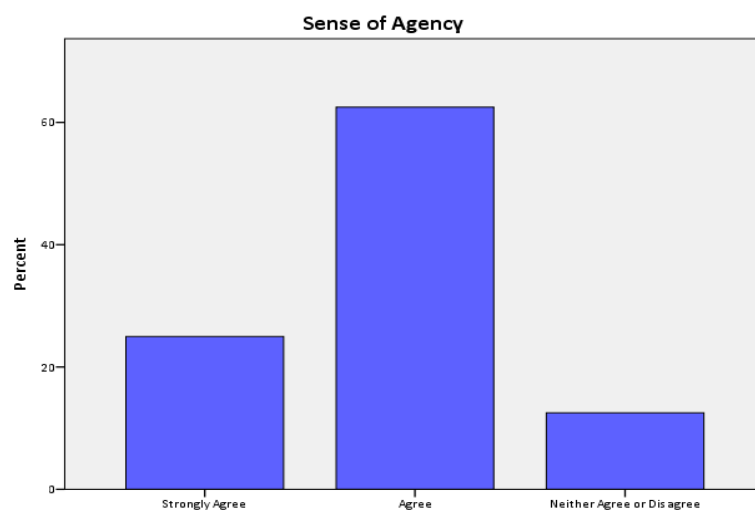


Nineteen per cent of the staff said they cared for people with dementia all of the time, seventy-five per cent said they often care for people with dementia and six per cent said they sometimes care for people with dementia.

Members of staff participating in a ward project were asked to respond to the following statements in order to provide feedback on the value of the Somerset Collaborative Dementia Care Project for enhancing their professional development.

Graph 14: Agency

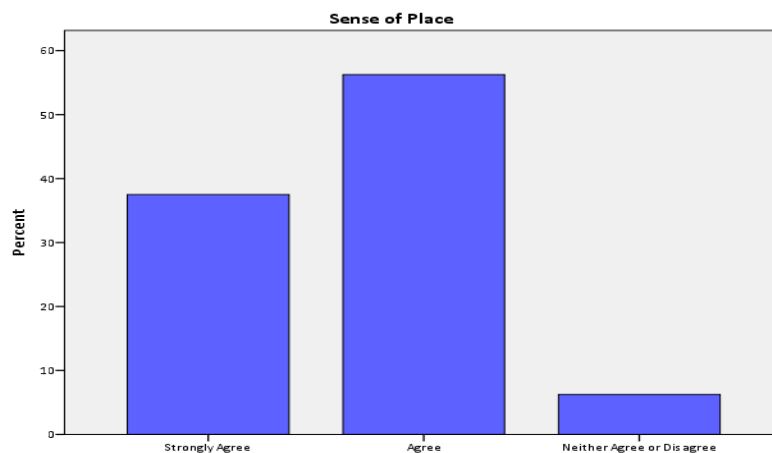
Through engagement with the project I have become more confident that I can help people with dementia have more say in their care in an everyday way.



As a result of taking part in the project eighty per cent of the staff agreed they could help people with dementia to have more say in their care.

Graph 15: Sense of Place

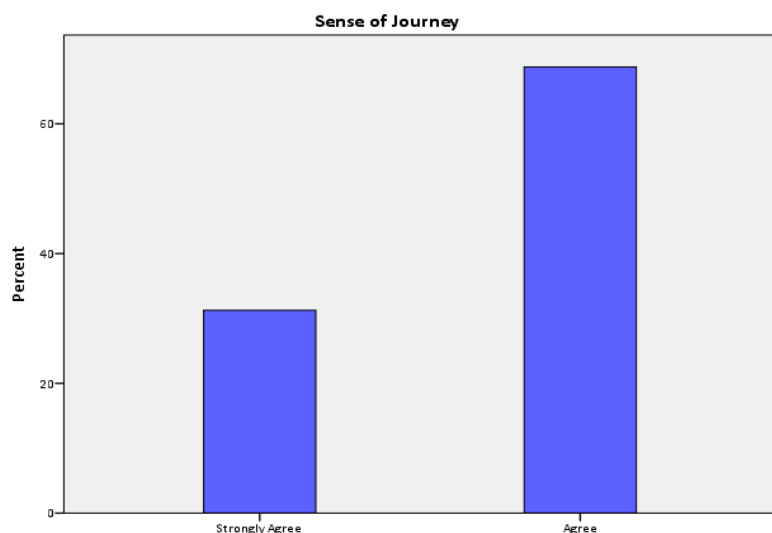
Through engagement with the project I have become more confident that I can make people with dementia to feel more at home in the places that they receive care.



As a result of taking part in the project ninety-four per cent of the staff agreed that they could help people with dementia to feel more at home in the place they received care.

Graph 16: Sense of Journey

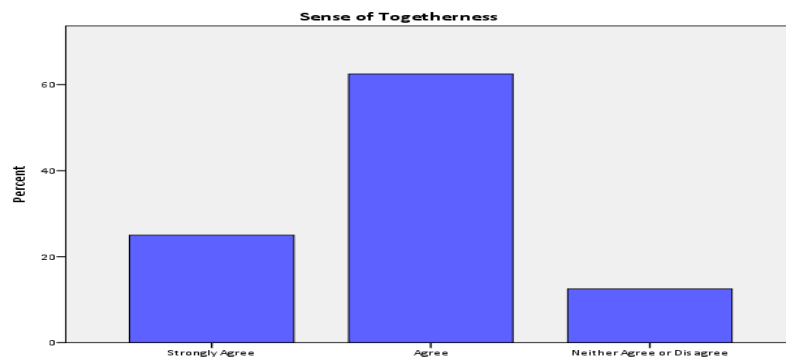
Through engagement with the project I have become more confident that my care and treatment of a person with dementia takes into account their life history as well as what has gone before in their care.



As a result of taking part in the project thirty-one per cent of the staff strongly agreed and thirty-one per cent agreed that they could base their care and treatment on the life history of the person with dementia and what had gone before in their care.

Graph 17: Togetherness

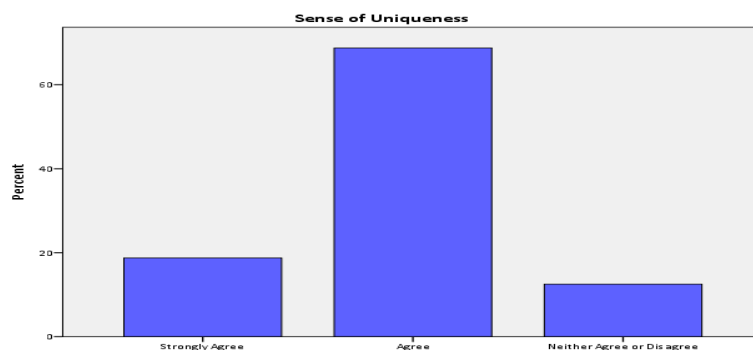
Through engagement with the project I have become more confident that I can help people with dementia feel more connected to the people that matter to them and their lives outside healthcare.



As a result of taking part in the project eighty-eight per cent of the staff agreed that they could help people with dementia feel more connected to the people that matter to them.

Graph 18: Uniqueness

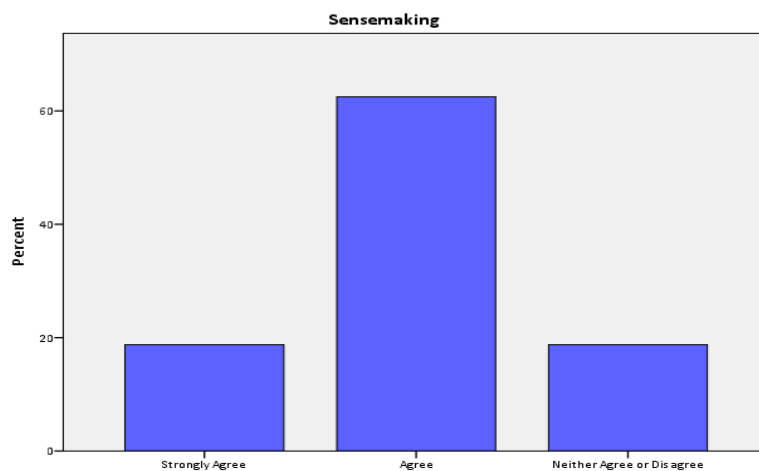
Through engagement with the project I have become more confident that I can help people with dementia feel that their specific and individual needs are being addressed.



As a result of taking part in the project eighty-eight per cent of the staff agreed that they could help people with dementia feel that their specific and individual needs are being addressed.

Graph 19: Sensemaking

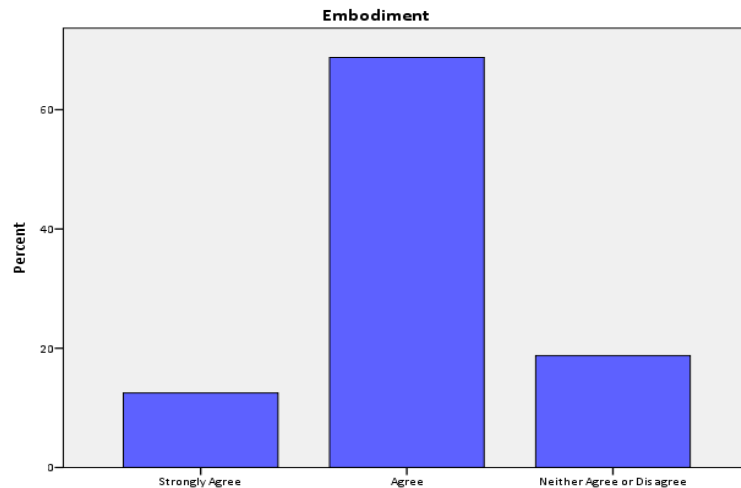
Through engagement with the project I have become more aware of the kind of information it is important to give people with dementia so that their treatment makes sense to them.



As a result of taking part in the project eighty two per cent of the staff agreed that they had become more aware of the kind of information it is important to give people with dementia so that their treatment makes sense to them.

Graph 20: Embodiment

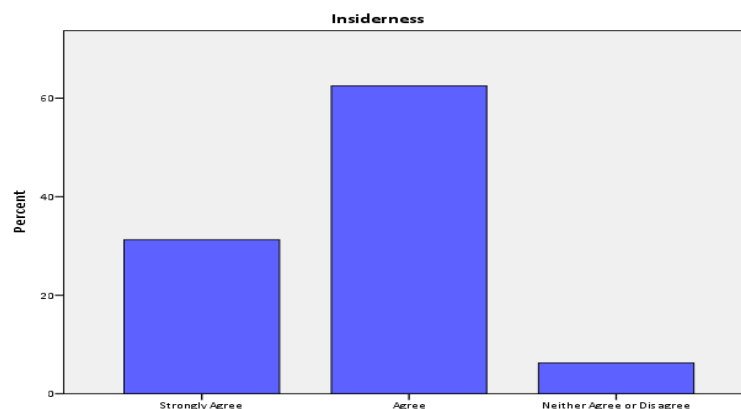
Through engagement with the project I have become more confident that I can enable people with dementia to feel that their care is directed to their life and well-being and not just to the alleviation of symptoms.



As a result of taking part in the project eighty-two per cent of the staff agreed that they could enable people with dementia to feel that that their care is directed to their life and well-being and not just to the alleviation of symptoms.

Graph 21: Insideriness

Through engagement with the project I have become more confident that I am able to see things from the perspective of the person living with dementia and am able to respond more empathically on the basis of this understanding.

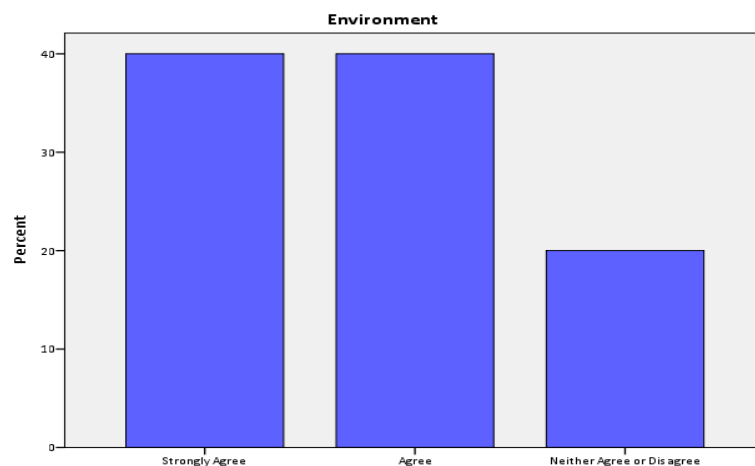


As a result of taking part in the project ninety-four per cent of the staff agreed that were able to see things from the perspective of the person living with dementia and were able to respond more empathically on the basis of this understanding.

In addition to these core questions staff were also asked to respond to statements that were specific to the project adopted for their ward.

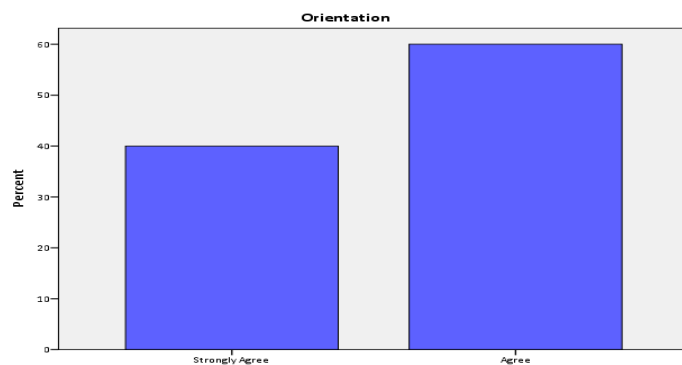
Environment Projects

Graph 22: Through engagement with the project I have become more aware of how the environment impacts on people with dementia.



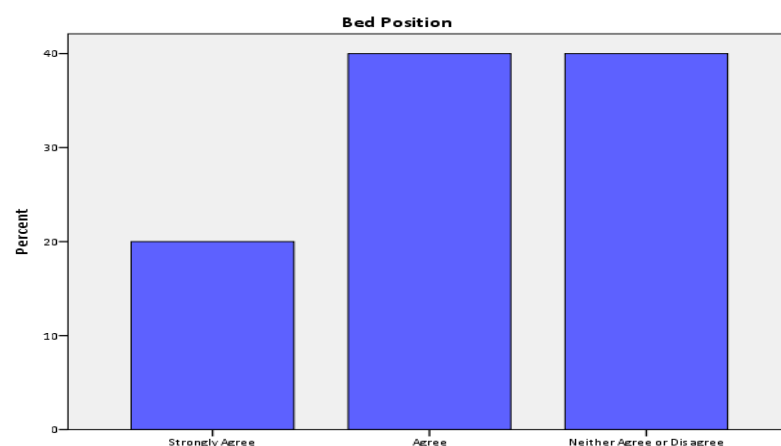
As a result of taking part in an environmental project eighty per cent of the staff agreed that they had become more aware of how the environment impacts on people with dementia.

Graph 23: Through engagement with the project I have become more aware of how a number of simple changes to the environment can have a positive impact on a patient's sense of orientation.



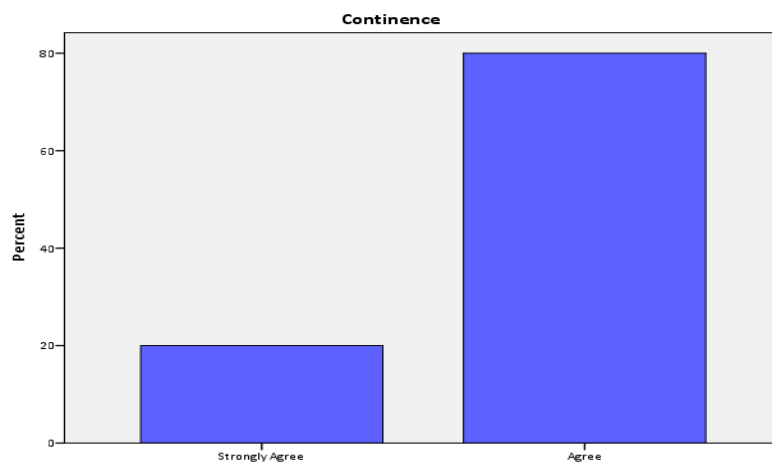
As a result of taking part in an environmental project forty per cent of the staff strongly agreed and sixty per cent of the staff agreed that they had become more aware of how a number of simple changes to the environment can have a positive impact on a patient's sense of orientation.

Graph 24: Through engagement with the project I have developed a greater awareness of the importance of the position of a patients' bed in the clinical area for the patient's wellbeing.



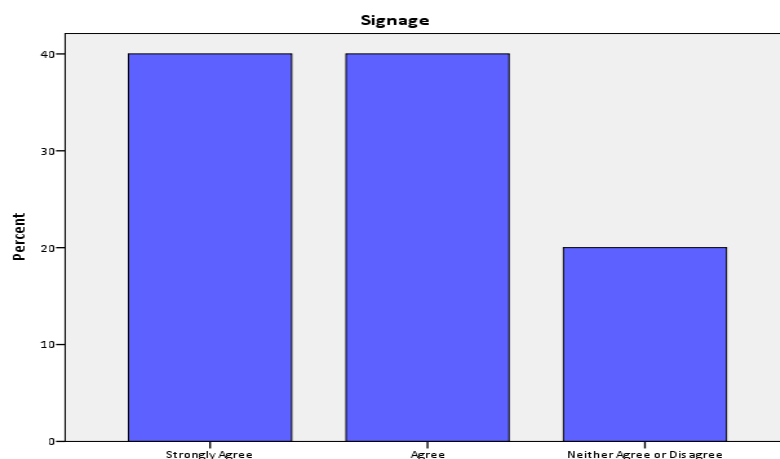
As a result of taking part in an environmental project sixty per cent of the staff agreed that they had developed a greater awareness of the importance of the position of a patient's bed in the clinical area for the patient's wellbeing.

Graph 25: Through engagement with the project I have become aware of how a number of changes made to the environment can improve continence.



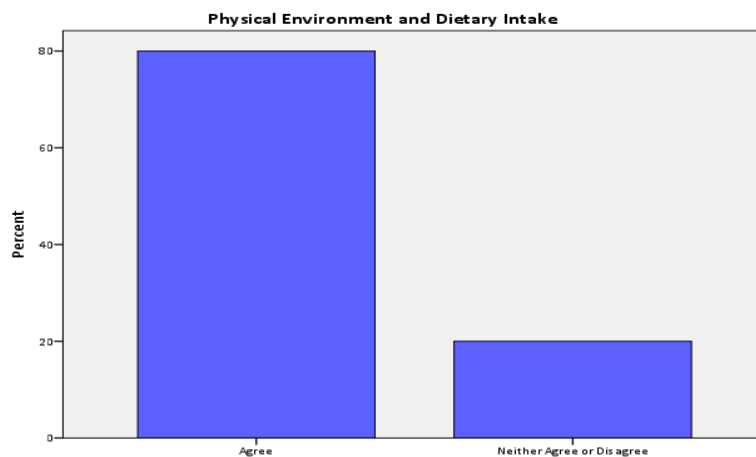
As a result of taking part in an environmental project twenty percent of the staff strongly agreed and eighty per cent of the staff agreed that they had become aware of how a number of changes made to the environment can improve continence in patients with dementia.

Graph 26: Through engagement with the project I have become more aware of how signage can help people with dementia.



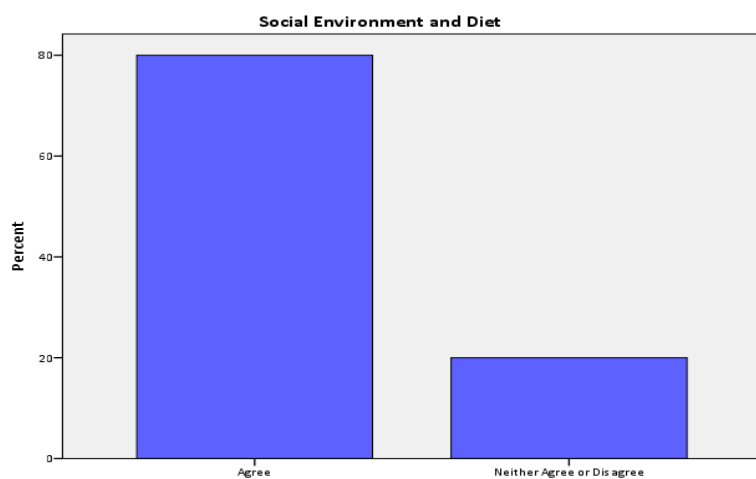
As a result of taking part in an environmental project eighty per cent of the staff agreed that they had become more aware of how signage can help people with dementia.

Graph 27: Through engagement with the project I have become aware of how the physical environment has an effect on dietary intake.



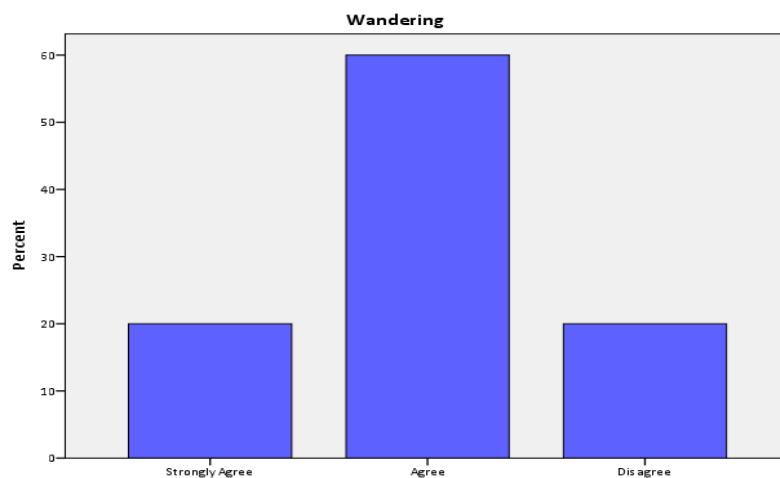
As a result of taking part in an environmental project eighty per cent of the staff agreed that they had become more aware of how the physical environment has an effect on dietary intake.

Graph 28: Through engagement with the project I have become more aware of how cues in the social environment have an effect on dietary intake.



As a result of taking part in an environmental project eighty per cent of the staff agreed that they had become more aware of how cues in the social environment have an effect on dietary intake.

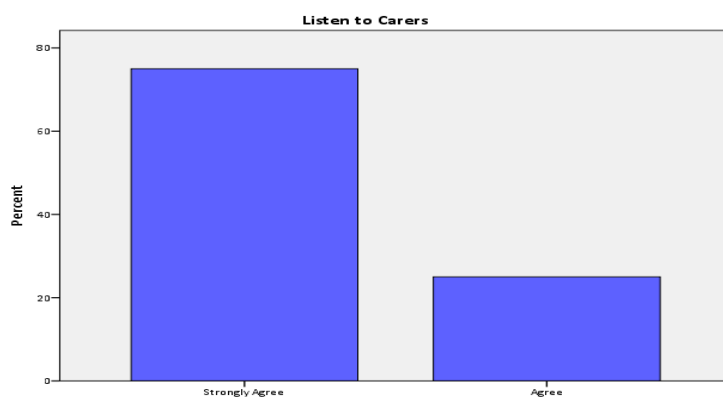
Graph 29: Through engagement with the project I have become more aware of useful strategies to use when a patient is wandering.



As a result of taking part in an environmental project twenty per cent of staff strongly agreed and sixty per cent of staff agreed that they had become more aware of useful strategies to use when a patient is wandering.

Carers Projects

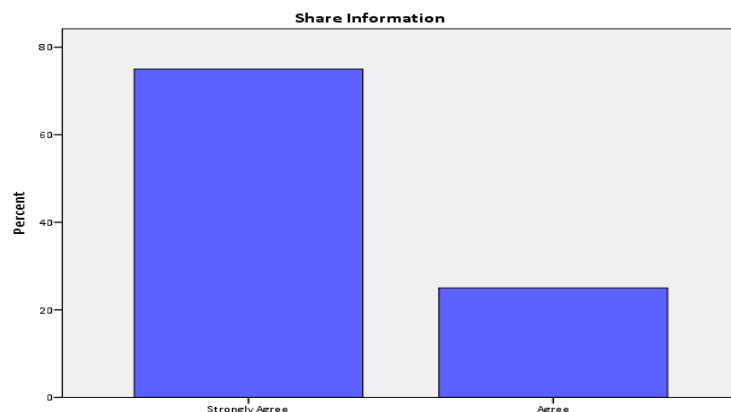
Graph 30: Through engagement with the project I have learnt the importance of listening to carers regarding what they see as important regarding their loved one with dementia and their care.



As a result of taking part in a carers project seventy five per cent of staff strongly agreed and twenty five per cent agreed that they had learnt the importance of listening to carers

regarding what they see as important regarding their loved one with dementia and their care.

Graph 31: Through engagement with the project I have learnt the importance of recording, sharing and passing on information from carers.



As a result of taking part in a carers project seventy five per cent of staff strongly agreed and twenty five per cent agreed that they had learnt the importance of recording, sharing and passing on information from carers.

Through engagement with the project I have learnt more about how a carer may find their loved ones stay in hospital stressful.

As a result of taking part in a carers project a hundred per cent of the staff strongly agreed that they had learnt more about how a carer may find their loved ones stay in hospital stressful.

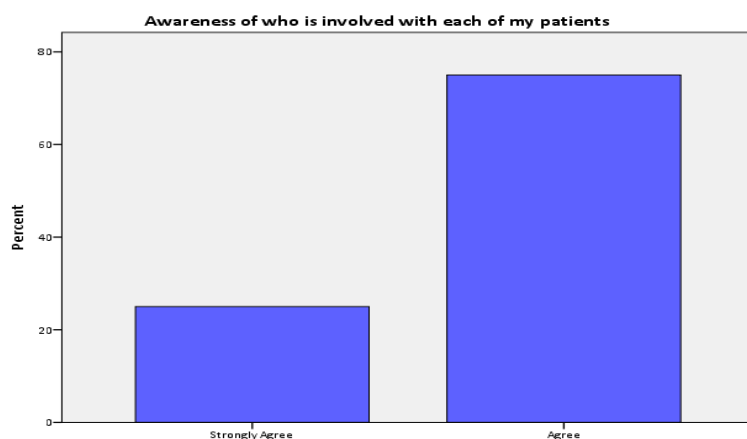
Through engagement with the project I have developed more confidence that I can recognize and help alleviate carers anxieties.

As a result of taking part in a carers project fifty per cent of staff strongly agreed and fifty per cent agreed that they had developed more confidence that I can recognize and help alleviate carers anxieties.

Through engagement with the project I have more awareness of how important it is to be open with carers regarding any difficulties we may be having with their loved one.

As a result of taking part in a carers project fifty per cent of staff strongly agreed and fifty per cent agreed that they had more awareness of how important it is to be open with carers regarding any difficulties we may be having with their loved one.

Graph 32: Through engagement with the project I have more awareness of who is involved with each of my patients and what resources and information it is important to get from them.



As a result of taking part in a carers project twenty-five per cent of staff strongly agreed and seventy-five per cent agreed that they had more awareness of who was involved with each of their patients and what resources and information it is important to get from them.

Occupation Projects

Through engagement with the project I have learnt that providing structure to everyday routines can enhance wellbeing.

As a result of taking part in an occupation project fifty per cent of staff agreed that providing structure to everyday routines could enhance wellbeing.

Through engagement with the project I have become more confident that I can engage in conversations with people with dementia using information from their personal history.

As a result of taking part in an occupation project a hundred per cent of staff agreed that they could engage in conversations with people with dementia using information from their personal history.

Through engagement with the project I have become more confident about how to help people with dementia by encouraging them to maintain their skills in personal care (i.e. washing, dressing, eating and drinking).

As a result of taking part in an occupation project a hundred per cent of staff agreed they had become more confident about how to help people with dementia by encouraging them to maintain their skills in personal care (i.e. washing, dressing, eating and drinking).

Through engagement with the project I have become more confident about how to engage people with dementia in meaningful social activities in and around the ward.

As a result of taking part in an occupation project a hundred per cent of staff agreed they had become more confident about how to engage people with dementia in meaningful social activities in and around the ward.

Through engagement with the project I have learnt to use a range of material available on the ward to encourage occupation (i.e. newspapers, books, television, board games).

As a result of taking part in an occupation project fifty per cent of staff agreed they had learnt use a range of material available on the ward to encourage occupation (i.e. newspapers, books, television, board games).

Through engagement with the project I have become more confident about assessing the well being of a person with dementia.

As a result of taking part in an occupation project fifty per cent of staff agreed they had become more confident about assessing the well being of a person with dementia.

The Somerset Collaborative for Dementia Care Workspace

The workspace on Huddle.net became active towards the end of the one-year initiative and is 'very much in its infancy'. The following groups received e mails through Huddle.net inviting them to participate in the workspace, members of the Steering Group, Dementia Champions/Leads from hospitals within Somerset, staff involved in ward-based projects and staff from Bournemouth University. To date forty-two people have responded to the invitation to participate.

The project facilitators were responsible for uploading files containing national papers, policy documents, training opportunities and individual folders containing the training material relating to ward-based projects and, web links to sites of interest. To date four discussions, have been initiated by the project facilitators, which have received limited responses, currently the last response was left on 5th April 2011. The project facilitators have added events to the whiteboard. It is not possible to ascertain how often the training materials have been accessed.

An initial barrier to use was identified as the initial invitation to participate being sent from huddle.net and as such there was a danger that:-

'....not everyone recognised the e mail..... as something legitimate,quite a lot of people, y'know deleted it'

Summary and Conclusions

Successive reports have highlighted the need for an informed and trained workforce to cope with the rising number of people with dementia, who are admitted to hospital for an underlying medical health condition. The aims of the Somerset Dementia Collaborative were to improve the hospital experience for patients with dementia, their carers and, families by developing staff awareness and confidence in caring for patients with dementia, through the creation of a sustainable network for learning.

In response to these aims, the two project facilitators developed an initiative to deepen people's perspective of dementia patients' needs by creating an awareness of what it might be like to be a patient with dementia on a hospital ward. This was achieved through the delivery of Lived Experience Workshops, the facilitation of Ward Projects, and the creation of an online network on Huddle.net. A 'Humanisation Framework' was used to guide the overall process.

A participative approach was taken for the overall improvement project. The traditional model of achieving change within the NHS tends to be a top-down, target driven approach. In this project staff were supported to take 'ownership' of their own individual projects. Initially staff found it difficult not having defined boundaries and set goals to work within. However with the support of the two key project facilitators they took 'ownership' of their individual ward-based projects and produced action plans that were responsive to the challenges they faced on their own particular wards. As one of the project facilitators commented, 'that's quite a big achievement because I think a lot of the time the people on the ward know what works and what can help'. The preparation of action plans encouraged staff to look more globally at their ward environment, resulting in them making changes in areas outside of the specific project they had chosen to implement. Engaging in effective communication with carers and family members at the earliest opportunity and the use of the 'This is me' booklet supported staff to deliver a more humanized form of care, based on the patients' history. Staff also became aware that making small changes to the environment could have a positive impact on patient experience. The project has also

supported staff to engage with patients with dementia as they have become more aware of, and sensitive to their human needs.

The findings from the evaluation have highlighted a number of possible directions for the future.

Recommendations

- Future staff development would benefit from further approaches to education that are based on the framework for the humanisation of care.
- Future improvement projects recruit skilled and dedicated members of staff to lead and support ward based staff to deliver changes and new initiatives and learn together through these projects.
- Encourage a move away from the didactic form of teaching to a model of staff development that is facilitative and hands on and therefore is more bottom-up and where groups of staff decide together on what can be achieved and how to achieve it.
- ‘Lived Experience Workshops’ should become embedded in the education curriculum for all staff working on hospital wards.
- Further workshops could be devised to expand on the learning gained in the Lived Experience Workshops to support staff working with patients who have more advanced dementia.

- Encouragement to use the information and training materials on the Somerset Collaborative Workspace 'Huddle.net' to initiate further ward-based projects.
- To fully exploit the value of 'Huddle.net' and to achieve sustainability of the overall project through the projects ability to encourage practitioners to share information and ideas across the geographical areas of the Somerset Partnership.
- Continued use of the 'This is me Tool' to support proactive communication with carers.
- Further recruitment of volunteers to support ward activities.
- A future study could concentrate on the sustainability and longer term benefits of the project, with a particular focus on benefit for patients and their carers and families. It is too early to evaluate this latter focus on patient benefit.

Conclusion

In the space of one year this innovative project met its aims to improve the experience of people with dementia and their carers during their hospital stay through staff training, ward change projects, and the development of an online resource.

The Lived Experience Workshops moved away from the formal approach to education by adopting a novel approach, allowing workshop participants to *'step into the shoes'* of a person with dementia and see the person behind the *'diagnosis of dementia'*. This understanding has been underpinned by the adoption of the "This is me" booklet, which contains information about the person supporting staff to deliver individualized care based

on the humanising strategies proposed by Todres *et al* (2009). The ward based projects were successful in facilitating a process whereby staff could creatively introduce changes in practice that had the potential to meaningfully improve experiences of people with dementia and their family members when they are admitted to a general or a community hospital.

The overall success of the Somerset Collaborative for Dementia Care Project lies in its multi-agency approach, which has seen a number of agencies coming together and working collaboratively to support the aims of project, and the two specialist project facilitators. A member of the steering group acknowledged that: -

‘this has been a very powerful project, and where as the outcomes around the individual wards might seem quite small, in reality what they have done is influence a much wider cultural change and focus the changing attitudes around dementia care at local level’.

The project has been responsible for influencing a number of other initiatives that have taken place outside of the ward-based projects in some of the participating hospitals these include: -

- An Hour to Remember (A dementia raising awareness session delivered to over 1100 hospital staff and nursing home staff)
- The use of the ‘This is Me’ tool being rolled out across the Trust
- End of Life Care - Advanced Care Planning for Patients with Dementia
- Development of Dementia ‘Be-Frienders’ (Volunteers)
- Development of Dementia Care Pathway

The enthusiasm and hard work of the two members of staff who facilitated the project was highlighted and they were commended for their approach: -

‘they’ve been able to impart their knowledge without making us feel like we don’t know what we are doing and I don’t think you can underestimate the importance of that’

In summing up their achievements over the year it was recognized that: -

‘..... the success of projects is not just about good project plans, and good partnerships with universities, it is actually about the individuals and they’ve really made that work’.

Finally, the overall sense of the evaluation suggests that it is not so much the details of the initiatives that came out of the projects that are the most important legacy of the collaboration but rather the difficult to measure enthusiasm, creativity and engagement that were generated from the kind of approach that was used.

The momentum for change that has occurred during the short life of the project has been immense but it now needs to be nurtured and taken forward, there are -

‘lots of little seeds growing and they need to be protected and allowed to grow now and that’s a challenge for all the organizations involved in the project’.

References

Adams, T. (2005). From person-centred care to relationship centred care. *Generations Review*, 15, 4-7

Alzheimer's Society. (2007). *Dementia UK: The Full Report*, London, The Alzheimer's Society

Alzheimer's Society. (2008). *Dementia, Out of the Shadows*, London, The Alzheimer's Society

Bartlett, R. & O'Connor, D. (2010). *Broadening the dementia debate: towards social citizenship*, Bristol, The Policy Press

Brooker, D. & Surr, C. (2005). *Dementia Care Mapping: Principles and Practice*, University of Bradford, Bradford

Cash, M. A. (2009). *Liberating qualitative research findings from the dusty shelf of academia: developing a translational methodology illustrated by a case study of the experience of living with dementia*. PhD Thesis (PhD), Bournemouth University

Department of Health (2008). *The Operating Framework for 2009/10 for the NHS in England High Quality Care for All*, London, (TSO)

Department of Health (2009a). *Living well with dementia – A National Dementia Strategy*, London, (TSO)

Department of Health (2009b). *Living well with dementia – the National Dementia Strategy Joint Commissioning Framework for Dementia*, London, (TSO)

Holloway, I. & Wheeler, S. (2010) *Qualitative Research in Nursing and Healthcare*, 3rd Edition, Chichester, Wiley & Blackwell

National Audit Office (2007). *Improving Services & Support for People with Dementia*, London, Stationary Office

NHS Somerset (2010). *Somerset Dementia Strategy*,
www.somerset.nhs.uk/EasySiteWeb/GatewayLink.aspx?alld=10866, accessed 16/5/2011

Royal College of Psychiatrists (2005). *Who Cares Wins, Guidelines for the development of Liaison Mental Health Services for older people*, Royal College of Psychiatrists

Todres, L. Galvin, K. and Holloway, I. (2009) .The Humanisation of Healthcare: A value framework for Qualitative Research, *International Journal of Qualitative Studies on Health and Well-being* 4(2), 68-77.

Appendix 1: Example of a Ward Action Plan

Ward Based Dementia Care Project: Occupation Action Plan			
Topic	Agreed Actions	By Whom /Date	Progress

TRAINING 1. Identify sources of ‘foundation training’ for all staff	<ul style="list-style-type: none">• Explore online and learning package options• Research Stirling University programme for HCAs• Review links to Dementia Gateway etc.• Raise at CHWG with x Dementia Lead re: SCH approach• Discuss with CPN link• Contact local SRC home manager to arrange staff ‘shadow’ visits/ on-site training sessions Research modules available at local universities / distance learning and identify costs.	
------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Topic	Agreed Actions	By Whom / Date	Progress
<p>RESOURCES</p> <p>1. Ensure activity resources are available to all patients and that these are varied enough to provide for all needs.</p>	<ul style="list-style-type: none"> • Review resources in Quiet Room • Identify any 'gaps' and make a list of items required • Obtain reminiscence materials such as DVDs, photographs, books from specialist suppliers or shops. • All members of the group to look for suitable items • Purchase DVD player and additional CD players for dayroom use. 	<p>ALL</p>	<p>Need to review list and agree purchases at next meeting on</p> <p>21.01.2011</p>

Topic	Agreed Actions	By Whom/ Date	Progress
ACTIVITY SESSIONS	<ul style="list-style-type: none"> • Contact volunteers • Agree programme of activities – Christmas crafts • Obtain craft items and arrange staff involvement and volunteer help. • Arrange volunteer meeting to seek help from existing volunteers who may be interested in this project – to update them on aims, offer training and discuss other potential activities 	Completed December 2010	<p>2 sessions completed prior to Christmas</p> <p>Making decorations from dough</p> <p>Making Christmas cards</p> <p>This was enjoyed by several patients who were well enough to participate.</p>
<p>1. Arrange trial activity programme on ward involving ward volunteers</p> <p>2. Make the most of existing activities on the ward such as the weekly exercise class – ensure those leading groups understand the needs of patients with cognitive impairment and how to make the session inclusive. Develop new sessions led by volunteers.</p> <p>3. Develop links to local SRC with expertise in activity programmes for training and advice</p>	<ul style="list-style-type: none"> • Contact manager at x SRC 	<p>End February 2011</p> <p>– Complete</p>	<p>Invitation letter to be sent W/E 21.01.2011</p> <p>Initial discussion positive</p> <p>Training date/s to be agreed</p>

Version 2: Updated 19 January 2011

Appendix 2: Questionnaires



Introduction

Thank you for participating in this survey about your experience of the 'Somerset Improvement Collaborative for Dementia' initiative. You have been asked to complete the enclosed questionnaire as a member of staff from an area that is taking part in the project by attending a workshop/ training event. This will give us valuable feedback about the value of the initiative for enhancing the professional development of staff working in settings that include the care of people with dementia. This is not a survey to find out your skills and knowledge; there are no right or wrong answers. Rather this survey is designed to obtain your views and reflections about some aspects of care of people with dementia and your views about what engagement in this project means to you. This will enable us to better understand what the project was able to achieve and not achieve in your particular case, and to improve development opportunities for staff in the future. All the responses will be anonymised and the data is only made available to the project team.

Thank you again for taking part.

Project Team

Jan Seewooruttun	Dementia Project Manager Older People's Service, Chantry House, Park Road, Frome, BA11 1EY	Janet.Seewooruttun@sompar.nhs.uk Tel: 01373 455801 / Mob 07786 702976
Jason Weetch	Clinical Lead Stonecross, Selbourne Place, Minehead TA24 5TY	Jason.Weetch@sompar.nhs.uk Tel: 01643 704971
Les Todres	Centre for Qualitative Research, Bournemouth University	ltodres@bournemouth.ac.uk Tel: 01202 962169
Kate Galvin	Centre for Qualitative Research, Bournemouth University	kgalvin@bournemouth.ac.uk Tel: 01202 962167
Marilyn Cash	Centre for Qualitative Research, Bournemouth University	mcash@bournemouth.ac.uk Tel: 01202 962035

(Lived experience workshop)

Please indicate which Facility / Ward you are attached to	
-----------------------------------------------------------	--

Please indicate your answer by circling the relevant response:

1. Age: 18-24 25-30 31-35 36-40
41-45 46-50 51-55 56 +
2. Gender: Female Male
3. Employment status: Full-time / Permanent Part-time Agency
4. Current Position:
5. Length of experience
0-12 months 1-2 years 3-5 years 6-10years
11-15 years 16-20 years 21 years and over
6. Length of experience working in this unit:
0-12 months 1-2 years 3-5 years 6-10 years
11-15 years 16-20 years 21 years and over
7. Length of work experience at this hospital/service:
Less than 3 months 3-6 months 6 months - 1 year
1-3 years 4-5 years 6-10 years more than 10 years
8. In your present job, how many hours do you work in a typical week? _____hrs
9. In the last year, have you cared for people with dementia?
All the time Often Sometimes Rarely Not at all
10. In the last year, have you experienced any difficulty in understanding people with dementia?
All the time Often Sometimes Rarely Not at all
11. In the last two years, have you attended any courses or training in dementia care?
None 1-2 3 or more

Instructions

Please provide your response to the following statements by circling one of the options in the boxes that corresponds to your view. Please circle one response per statement.

Each statement is an opportunity for you to offer your views about aspects of dementia care and the meaning of the experience of engaging with the project for your professional development.

Humanising strategies**Agency:**

Through engagement with the project I have become more confident that I can help people with dementia have more say in their care in an everyday way.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

Sense of Place:

Through engagement with the project I have become more confident that I can make people with dementia to feel more at home in the places that they receive care.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

Sense of journey:

Through engagement with the project I have become more confident that my care and treatment of a person with dementia takes into account their life history as well as what has gone before in their care.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

Togetherness:

Through engagement with the project I have become more confident that I can help people with dementia feel more connected to the people that matter to them and their lives outside healthcare.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

Uniqueness:

Through engagement with the project I have become more confident that I can help people with dementia feel that their specific and individual needs are being addressed.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

Sensemaking:

Through engagement with the project I have become more aware of the kind of information it is important to give people with dementia so that their treatment makes sense to them.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

Embodiment:

Through engagement with the project, I have become more confident that I can enable people with dementia to feel that their care is directed to their life and well-being and not just to the alleviation of symptoms.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Insiderness:

Through engagement with the project I have become more confident that I am able to see things from the perspective of the person living with dementia and am able to respond more empathically on the basis of this understanding.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Additional Questions for Staff Participating in a Ward-Project relating to Carers

Through engagement with the project I have learnt more about the importance of listening to carers regarding what they see as important regarding their loved one with dementia and their care.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have learnt the importance of recording, sharing and passing on, information from carers.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have learnt more about how the carer may find their loved ones stay in hospital stressful.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have developed more confidence that I can recognize and help alleviate carers' anxieties.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have more awareness of how important it is to be open with carers, regarding any difficulties we may be having with their loved one.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have more awareness of who is involved with each of my patients and what resources and information it is important to get from them.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Additional Questions for Staff Participating in a Ward-Project relating to the Environment

Though engagement with the project I have become more aware of how the environment impacts on people with dementia.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have become more aware of how a number of simple changes to the environment can have a positive impact on a patient's sense of orientation.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have developed a greater awareness of the importance of the position of a patients bed in the clinical area for the patients well-being.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have become more aware of how a number of changes made to the environment can improve continence.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have become more aware of how signage can help people with dementia.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have become more aware of how the physical environment has an effect on dietary intake.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have become more aware of cues in the social environment has an affect on dietary intake for people with dementia.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engagement with the project I have become more aware of useful strategies to use when a patient is 'wandering'.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Additional Questions for Staff Participating in a Ward-Project relating to Occupation

Through engaging with this project I have learnt that providing structure to everyday routines can enhance wellbeing.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engaging with this project I have become more confident that I can engage in conversations with a person with dementia, using information from their personal history.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engaging with this project I have become more confident about how to help people with dementia by encouraging them to maintain their skills in personal care i.e washing, dressing, eating and drinking.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engaging with this project I have become more confident about how to engage people with dementia in meaningful social activities in and around the ward.

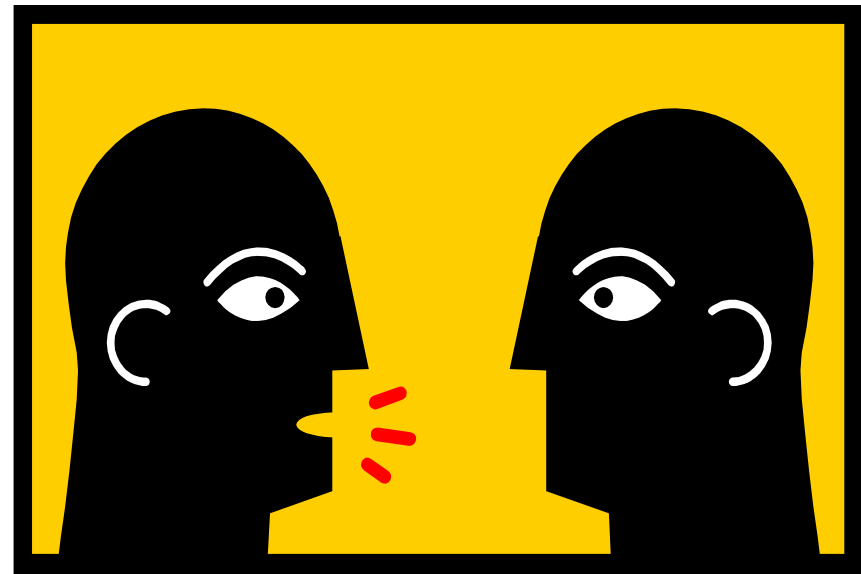
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engaging with this project I have learnt to use a range of material available on the ward to encourage occupation i.e newspapers, books, televisions, board games.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------

Through engaging with this project I have become more confident about assessing the wellbeing of a person with dementia.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
----------------	-------	-------------------------------	----------	----------------------



DEMENTIA PROJECT

COMMUNICATION IDEALS

THE LANGUAGE OF DIGNITY

Trudy Bower

ISBN 978-1-85899-281-5



Introduction

Just try to imagine for a moment you are in a place that you don't recognise, there are people around you but you don't know them, these strangers are talking to you, but you can't talk back your words are stuck, you are unable to speak, the few words that come out of your mouth are jumbled up. You're frightened, scared and lonely. This is how it sometimes feels when you have Dementia even the normal every day things are unrecognisable, you're being asked do you want a cup of tea (tea) do you eat this or drink this, you're not sure, sugar do you take sugar, tea, sugar, what are these people on about. Now you're being asked do you need the toilet, they are standing you up and leading you to a small room, but you don't know where you're to, this stranger then says here we are, here's the toilet let me help you, they start to pull at your cloths, what are they doing, you're panicking, you want to say leave me alone, I can do that, but your words won't come out, where's my mum I am safe when I think of my mum and dad.

Communication

Problems with communication, memory, awareness, sense of time etc are all part of dementia.

When people can't remember, they can't stay reassured, so when you're talking with someone with dementia you need to provide the reassurance:

With words

By showing them what they need to see

By communicating in your gestures

By your tone of voice

By giving them extra time

By finding out interests of theirs

By listening to the same thing several times

Do's and don'ts

Do's

- * Do say, Thank you for telling me.
- * Do say, what a nice colour your jumper is
- * Do say, it's nice to see you
- * Do say, I really enjoyed talking with you
- * Do ask if they want to watch some television
- * Do say, do you want to see what's going on over there
- * Do say, I'm going to have a little walk, would you like to come with me?
- * Do be patient
- * Do let them be the host/hostess
- * Do let them talk
- * Do show respect

Communication

Problems with communication, memory, awareness, sense of time etc are all part of Dementia.

When people can't remember, they can't stay reassured, so when you are talking with someone with Dementia you need to provide the reassurance:

- * With words
- * By showing them what they need to see
- * By communicating with your gestures
- * By your tone of voice
- * By giving them extra time
- * By finding out their interests
- * By listening to the same thing several times

LEARNING THE LANGUAGE

Don't Say

- * What did you have for lunch today?
- * What did you do today?
- * Is that a new skirt/trousers?
- * Who is that sitting over there?
- * Do you know who I am?
- * You just told me that.
- * I already know that.
- * What kind of music do you like?
- * We talked about this a moment ago.
- * I just explained that.
- * Do you want to watch (Coronation Street)?
- * I don't understand why you say things like that.
- * How many times have you walked up and down today?
- * Stop doing that.
- * You asked me that already!
- * You know I can't do that.

Your Answer

Acknowledge that it's scary to not remember anything but tell them:

- You'll think of it later.
- Let's do something else for a while.
- Our memories play tricks with us: my memory plays tricks with me sometimes

- Everything here is paid for already, so you have nothing to worry about.
- It's all paid for, isn't that great?

- Can I help you?
- Tell me what has upset you?

Of DIGNITY DO'S AND DON'TS

Their Questions

- I don't know what's happening to me. I can't seem to remember anything

- I don't know what to do: I don't have any money with me".

- Please help me. Can someone please help me?

- Are you going to be here tonight?

Do Say

*How was lunch today?

*How are you?

*What a nice jumper. I don't remember it.

*That person looks nice. Let's go and meet him/her

*Hi, I'm glad to see you

*That's interesting; I didn't know that.

*Thanks for telling me

*Would you like to listen to some music?

*Let me show you

*I'm not sure I got that. Could you explain it again?

*You look comfortable. Can I join you?

*Looks like you're enjoying your walk. Can I join you?

*That's an interesting question. I hadn't thought about it before.

*I really don't know what do you think?

*I wish I could, but I can't

THINGS A DEMENTIA PATIENT MAY SAY OR ASK

Their Question

- Please take me home

- I want to call my parents so they can pick me up”.

- I need to get out of here; is that the door?

- Do I know you?

- Who are you

Your Answer

I wish I could, but you need to stay here today.

(Don't tell the Dementia patient their parents have died, this would make them suffer the shock of grief and loss all over again) your reply:

- Your parents really loved you didn't they?
- Tell me about them

Let's go for a walk to see”, (when you're walking change the conversation to help them think of something else)

- No, we haven't met before, but it's nice to meet you.
- We only met once, but we didn't get a chance to talk, it's nice to have the chance now.

Tell them your name and that you are a (nurse)

Appendix No 4: The humanization of healthcare: A value framework for qualitative research

International Journal of Qualitative Studies on Health and Well-being. 2009; 4: 68–77

informa
healthcare

ORIGINAL ARTICLE

The humanization of healthcare: A value framework for qualitative research

LES TODRES Professor, KATHLEEN T. GALVIN Professor & IMMY HOLLOWAY Professor

Centre for Qualitative Research, Bournemouth University, UK

Abstract

Qualitative research, through its illumination of people's perspectives and experiences, has contributed a particular kind of useful evidence for caring practices. Until now however, it has found its location in healthcare without making the powerful impact on humanizing practice that is its key strength. Our paper develops a conceptual framework for humanizing care, and through examples illustrates an emerging agenda that moves qualitative research into its next and overdue phase: to enter policy-making; curricula in professional education; and to be meaningfully translated into practice in ways that place people as human beings at the centre of care. This paper provides eight philosophically informed dimensions of humanization, which together, form a framework that constitutes a comprehensive value base for considering both the potentially humanizing and dehumanizing elements in caring systems and interactions. In each case, we show, with reference to published studies, how qualitative research findings are already consistent with the humanizing focus articulated in our conceptual framework. We finally describe a reciprocal relationship in which the humanizing value framework guides a dedicated focus for qualitative research, and in which qualitative research in its turn, supports the humanising emphasis because of its intrinsic features.

Key words: *Humanization, qualitative research, phenomenology, philosophy of care*

Introduction

Research into health and healthcare has achieved substantial advancement in knowledge and improvements in care, through its focus on interventions, treatment and cure. Todres, Galvin and Dahlberg (2007) note how increasing specialization alongside technological advances and research have improved health and well-being. Alternatively, there is increasing evidence in the media and from qualitative research in particular, that the human dimensions of care can be obscured by a sometimes-necessary technological and specialized focus. Charon (2006) speaks of the "vexing failures of medicine—with its relentless positivism, its damaging reductionism, its appeal to the sciences and not to the humanities in the academy, and its wholesale refusal to take into account the human dimensions of illness and healing" (p. 193). It is within this context that the recently established Global Institute for Research in Humanizing Care Contexts has produced a

document that notes that the attempt to humanize healthcare requires a dedicated research focus (Morse, 2007).

In this paper, we wish to explore the productive mutual relationship between a humanizing value framework for health care and the practice of qualitative research. We aim to show (a) that a conceptual framework for humanizing health care may provide a dedicated focus for guiding both research and practice; and (b) that the nature of qualitative research is able to offer distinctive support to a humanizing emphasis for care. The paper is thus philosophical in emphasis even though it draws on examples from qualitative research in order to illustrate the concepts developed.

In developing our humanizing framework, we have been most influenced by the existential-phenomenological tradition, and sociological perspectives that have illuminated phenomena such as human agency, anomie and alienation. Our perspectives on "what it

Correspondence: L. Todres, School of Health and Social Care, Bournemouth University, Christchurch Road, Bournemouth BH13LT, UK. Tel: +44 (0)120-296-2169. E-mail: ltodres@bournemouth.ac.uk

(Accepted 24 November 2008)

ISSN 1748-2623 print/ISSN 1748-2631 online © 2009 Informa UK Ltd
DOI: 10.1080/17482620802646204

means to be human," have been centrally informed by the phenomenological tradition beginning with Husserl's (1936) notion of the lifeworld. His exposition of basic dimensions of the lifeworld such as embodiment, temporality and spatiality helped us think through what is irreducibly human. Further Heidegger's contemplations about human freedom, being with others and the authentic "ownness" of self (Heidegger, 1962) as well as Merleau Ponty's (1964) ideas about body subject and body object also helped us to develop some core dimensions that could be applied to health social care.

First, we develop a conceptual framework that articulates what we mean by the term "humanization" as a value base for guiding care. This provides eight philosophically informed dimensions of humanization, which together, form a framework that constitutes a comprehensive value base for considering both the potentially humanizing and dehumanizing elements in caring systems and interactions. In each case, we show, with reference to a number of published studies, how qualitative research findings are already consistent with the humanizing focus articulated in our conceptual framework.

Such a framework is particularly useful when mapping a significant and meaningful focus for a qualitative research programme. We would like to contribute to this development by considering the potential for qualitative research to address such a dedicated focus. As such, the value framework may serve as an important foundation for guiding qualitative research programmes. We will also argue, however, that there is something about qualitative research that is particularly conducive for supporting more humanizing emphasis in practices of care. We thus describe a reciprocal relationship between the value framework and qualitative research. This framework also reveals a possible new important emphasis in the history of qualitative research whereby care is not just guided by its traditional emic focus, but that the emic focus has now got to a historical stage of achievement in which important general ethical and humanizing themes from the findings of qualitative studies may guide care more generally.

A value framework for humanizing healthcare

In this section, we first consider what we mean when we use the term "humanization". We then offer eight dimensions, which articulate the essential constituents of humanization in relation to caring. Each dimension is heuristically expressed as a continuum stretching from the term that characterizes humanization in a positive sense; through to the term that characterizes the barrier to such a possibility. Even

though each of the dimensions is expressed as an assertion that has an opposite for the sake of clarity, we are not suggesting any dualism here. In other words, we are not suggesting that one is either "in a humanizing or dehumanizing moment" but rather that these bipolar terms suggest possibilities along a spectrum that have to be considered in context. Thus, we should like to emphasize that each dimension expresses a spectrum of possibilities that constitute "ideal" types. We are not suggesting these ideal types as absolute values but rather as touchstones for awareness when considering the complexity of lived situations. As such, we do not wish to over emphasize the negative value of what we have called dehumanizing practices, there may be appropriate times when these are necessary for effective care. For example, in an intensive care situation patients fully accept the necessity for professionals to focus exclusively on the technological definitions of their current bodily functioning at particular phases of their treatment (Tödres, Fulbrook & Albarran, 2000).

What do we mean by the term humanization?

To be concerned with humanization is to uphold a particular view or value of what it means to be human, and furthermore to find ways to act on this concern. Thus, we need to articulate the essential constituents of what it is to be human as a value base. A consideration of all the constituents taken together can then form a useful standard from which to judge the humanization of care. The judgement would include two levels: the extent to which care addresses all eight dimensions, and the extent to which care can be located somewhere along the continuum of each dimension's positive humanizing characteristic in relation to its more negative dehumanizing feature. Therefore, the following dimensions are not separate but imply one another; for sake of clarity, we highlight these nuances as important because they can be differentially emphasized or be de-emphasized in particular circumstances (Table I).

Dimensions of humanization/dehumanization

Each of the eight dimensions of humanization and dehumanization expresses a spectrum of possibilities. In each case, the positive humanizing value is first articulated, followed by how it may be obscured by a dehumanizing emphasis. Dehumanization occurs when any one or more of the humanizing dimensions are *obscured to a significant degree*. We should like to note here that the dimensions of humanization and dehumanization are not absolutes

Table I. Conceptual framework of the dimensions of humanisation.

Forms of humanization	Forms of dehumanization
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenization
Togetherness	Isolation
Sense-making	Loss of meaning
Personal journey	Loss of personal journey
Sense of place	Dislocation
Embodiment	Reductionist body

This table is just to help the reader imagine each dimension along a spectrum of possibility rather than indicating an either/or category in each case.

but rather a matter of emphasis. For instance we acknowledge that forms of assessment and other health care practices, which are problem solving in a technically helpful way, are important. However, it is when these technical problem strategies overshadow the humanizing dimension we refer to, that there is a *potential* for dehumanization. Each of the eight dimensions clearly overlap in some respects, but each emphasizes something special as captured in the name of the dimension in each case. Such distinctiveness is also indicated by the choice of example from the qualitative research literature. We searched the qualitative literature for everyday examples that would illustrate something distinctive about the specific dimension. There are numerous examples in the literature that could be used, so we “handpicked” examples that we thought would provide some understanding of how the dimension could be relevant to practice and situations.

Insiderness/objectification

What makes each of us intimately human is that we carry a view of living life from the inside. To be human is to live in a personal world that carries a sense of how things are for the person. Only individuals themselves can be the authorities of how this inward sense is for them. Such subjectivity is central to human beings’ sense of themselves. Our sense of feeling, mood and emotion is the lens by which our worlds are coloured. This provides important human textures for valuing the qualities of things. If such a dimension is neglected then something important is missing when responding to human need.

In *objectification*, people are made into objects by focusing excessively on how they fit into a diagnostic system, part of a statistical picture or any other strategy by which they are labelled and dealt with that does not fully take account of their insiderness. There is a whole psychology of how we separate ourselves from one another through dissociation by

emphasizing the distance between insider and outsider. For example, when nurses or doctors break bad news to a patient, and sit at the computer, they may focus the conversation on how the individuals fit with the statistics of their condition, the diagnostic category and other categories rather than attending to the meaning the bad news has for the person. Along our spectrum, this is an everyday example of how an objectifying interaction may happen. An extreme example of objectification is Arendt’s reference to the use of ‘office-speak’ by Nazi executioners when dealing with human beings in concentration camps while putting aside the work of the office before a family dinner (Arendt, 1963).

Another example of everyday objectification is shown by a qualitative study. Holloway, Sofaer and Walker (2007) examined the experiences and needs of people who suffered from chronic low back pain through interviews. Stigmatization by “the system” and health professionals as well as by significant others, emerged as a key theme from the narratives of participants. To be labelled as members of a group that were not only expensive to the system but also seen as “malingers” deeply affected the perception of self and self-esteem and the behaviour of the patients. The study demonstrated that pain management programmes need to take into account the feelings of participants to make them feel valued and accepted. It illustrates how labelling is one form of objectification.

Agency/passivity

To be human is to experience oneself as making choices and being generally held accountable for one’s actions. This constitutes a sense of agency in which we do not experience ourselves as merely passive or totally determined but have the possibility of freedom to be and act within certain limits. A sense of agency appears to be very closely linked to the human sense of dignity. When this is taken away, one’s sense of personhood is diminished.

In *passivity*, there is excessive emphasis on attitudes and practices that render the person passive in relation to their condition and treatment. Traditionally the medical model has emphasized a view of the person and the body as passively subjected to internal and external forces. The increasing emphasis on the user involvement movement in health and social care is a reaction to this view. Through excessive passivity, one is stripped of human dignity to varying degrees and this can be dehumanizing. For example, people with anorexia nervosa often rebel against the lack of dignity when an over concern with nutrition and weight gain infantilizes them in such a way, that they are excessively watched

and a sense of personal dignity becomes difficult to sustain.

What follows is an example of a study where practices have rendered individuals passive in relation to their condition and treatment. Johansson and Ekebergh (2006) described how women who were recovering from myocardial infarct, experienced well-being through being facilitated to influence and take responsibility for their own bodies after a period of acute care, which was characterized by insecurity and felt "pushed out" by their care situation. They were passively dependent on health care professionals and their knowledge, but need to regain control of their own health. A humanizing care is actively facilitating participation in their health process. The study illustrates how everyday care can be humanized by enhancing agency through increased patient participation.

Uniqueness/homogenization

To be human is to actualize a self that is unique; such uniqueness can never be reduced to a list of general attributes and characteristics. We are always more than the sum of the parts. No matter how much we are part of larger influences and contexts, there is something unique in space and time about this particular person in this particular moment that characterizes their particular individuality.

In *homogenization*, there is excessive focus on how the uniqueness of the person is de-emphasized in favour of how they fit into a particular group. In their concern to please, patients agree to looking at themselves or accepting practices in which their own uniqueness is de-emphasized so there is a kind of self-fulfilling prophecy. When this happens, uniqueness is no longer considered by self or other.

In order to "fit in", one may adopt the role of a "good patient" acting according to expectations, not complaining and complying with treatment. For example, there is long standing evidence that "unpopular" patients are labelled and placed into categories and experience worse treatment (Stockwell, 1984). There is also evidence of the tyranny of institutional authority: individuals develop a sick role (Parsons, 1951), become accepting, and submit to the authority of expert knowledge. This role reduces the creativity and imagination of the options that may be open to the sick person. In an early study, Rosenhan (1973) for instance, wished to show the extent of de-personalization and labelling in institutions. His study illustrated how "pseudo-patients actions", while under cover in psychiatric hospitals, were interpreted as pathological behaviour because of context; the "fake" patients were not recognized.

The following qualitative study is an example of loss of unique identity and everyday practices that emphasize how individuals fit into a particular diagnosis or homogeneous group. Phenomenographic research by Widang, Fridlund and Mårtensson (2008) showed that patients feared that they were seen as "the disease", "helpless", and "an individual suffering from cancer" rather than a person with other identities, such as for instance, "professional woman". The study illustrated that "maintaining the self" and retaining personal identity as a unique individual is necessary for people during illness. In interaction with their carers, the participants found it important to keep their dignity by means of retaining "the self" as a unique individual. This implied having some control over the situation related to what they themselves saw as important. This study illustrates the importance of a sense of personal uniqueness for well-being.

Togetherness/isolation

To be human is to be in community: our uniqueness exists in relation to others, and there is always an ongoing dialogue or "play" between what we have in common, and how we organize and make sense of this in very personal and unique ways. Togetherness and uniqueness imply one another and make meaningful the central human experiences of both aloneness and intimacy. In different ways and in different times, privacy, human connectedness and intimacy can be important. This dimension of togetherness makes possible the experience of empathy in which we can appreciate the suffering and struggles of "the other" who is also actively engaged in a personal world like ourselves with its own vicissitudes. Either commonality or uniqueness can be overemphasized and this has implications for care.

In *isolation*, we feel ourselves separated from our sense of belonging with others. Our everyday social connections are disrupted and we can feel lonely. What we have in common with others recedes from view and we can feel like strangers. In isolation, we feel alienation from others to varying degrees. It is inevitable that illness brings a sense of separation from taken for granted feelings of belonging with our intimate social world and significant others. Isolation however can then either be mitigated or exacerbated by different health care systems and practices. For example, any institutional bias with its sometimes necessary rules, safety procedures and concern for the efficient running of the system can take away a sense of belonging. In such circumstances, a person can feel dehumanized and cut off by the creation of an alternative culture that is alien to a sense of

everyday belonging. There are many practices whereby the social needs of communities with particular conditions are attended to, for example, social networking websites, special support groups and any ways in which a person can be treated within their everyday social networks.

What follows is an example of a study where practices emphasize an institutional culture that separates persons from their sense of familiar belonging. Williams and Irurita (2004), following a grounded theory study, describe a range of practices that led to isolation. Participants identified feeling devalued by activities such as lack of eye contact, standing at the end of the patients bed rather than beside them, serious or blank expressions, lack of touch, not having social conversation with the person, not remembering their personal details. In a further example, Del Barrio et al. (2004) have described how nurses can optimize positive experiences for liver transplant patients in intensive care by facilitating the presence of family members in the ICU at their bedside, as this qualitative study showed that the only social support patients wanted and needed was from their immediate family. These qualitative studies illustrate how a sense of human belonging can become vulnerable in institutional contexts and the need to support such belonging in practical ways.

Sense-making/loss of meaning

To be human is to care for the meaning of things, events and experiences for personal life. Such sense making involves an impetus or motivation to bring things together, to find significance and to make wholes out of parts. Within this context, we are story makers and storytellers. The search for narrative truth is often experienced as more humanly significant or felt to be more meaningful than the search for statistical truth. Sense making looks for *Gestalt* and patterns that connect. When such sense making is taken away from us in varying degrees, we can experience a sense of dislocation and meaninglessness. This can feel like being part of a machine or a "cog in the wheel". In finding patterns that connect for our lives we are acknowledging a certain seamlessness to living in which life cannot be essentially compartmentalized into the private and the public, concerns of body and concerns of mind, health care from social care, from economic care; human needs are holistic and transcend such differentiated discreet categories.

In *loss of meaning*, human beings become numbers and statistics. When we are counted as a statistic, our treatment often does not make sense to us, because what is important statistically does not necessarily connect with individual human experience. For

example within the UK, "a postcode lottery" has developed in which political and geographical considerations determine differential treatments. Apart from the general issue about lack of equity, in the present context, we wish to draw out the theme of "not making sense" from the patients' perspective. It does not make sense to people with cancer living in one part of the country that they cannot get the same treatment as another person living in a different part of the country. Statistical realities can produce inequalities because they are usually based on a utilitarian philosophy and are designed for large-scale representation and standardisation. When human beings are forced to fit into the standardised framework they often feel that it makes logical sense, but do not always experience practices of standardization as systems of *care*. Within this context there is also insufficient appreciation of how different systems of care, and the agencies within them, contribute to the fragmentation of "sense making" by the agencies and practitioners themselves feeling disconnected. Charmaz (2006) used a grounded theory approach to examine ordinary everyday pursuits of people with chronic illness. The purpose of this was to explore how people use past and present involvement in activity to form implicit and explicit meanings of their health, well-being and emerging selves. The study described how a sample of people with chronic illnesses, such as diabetes, multiple sclerosis and heart and circulatory disease, measured their everyday pursuits and involvements as indicators of their health and adopted these measures as markers of who they are and who they are becoming. The research illuminates how people were able to make sense of their health and well-being by taking their focus beyond their symptoms to looking at how they are doing within their larger lifeworld contexts.

Personal journey/loss of personal journey

To be human is to be on a journey. We live forward from the past; how we are in any moment which needs to be understood in the context of a before and a next. We move through time meaningfully and do not exist in a vacuum; to be human is to be connected to a sense of continuity. In addition, the future faces us as an unknown that offers the possibility of novelty and something different. To be human is to be connected to the familiarity of the past as well as to move into the unfamiliarity of the future. One can be oppressed by the past repeating itself and stultified by the familiarity of merely "more of the same". Alternatively, individuals can be dislocated and shocked by the unfamiliarity of events that excessively wrench them away from the familiar.

This engagement with temporality thus needs to be understood when considering a more humanized form of care; how the meaningfulness of a person's personal journey can either be supported or lost.

Loss of personal journey can happen when health care practices do not pay sufficient attention to the history and future possibility of a person's life. This manifests in an excessive emphasis on *how* the person is, not *who* the person is. For example in "snap shot" medical consultation individuals are separated from their normal social context and treated as cases rather than persons with a history and biography. In health care delivery systems, there is sometimes little room for considerations of continuity, or of how a person's sense of continuity is maintained. The focus is very much on the present. The trajectory of technological advances as well as demands on practitioners' time mean that a snap shot approach to health care conditions needs to be complemented, with a more biographical approach, which appreciates a person's history and importance of continuity: an increased emphasis on *whom* the person is. The feeling of knowing who they are helps people know and feel how their care is linked to their history. A dehumanizing practice also occurs where individuals are oppressed by sameness, routine and repetitious activity. A practitioner will keep on interacting with the patient in the same way and this reduces possibilities by experiencing oneself as being "more of the same". Medved and Brockmier (2008) interviewed adults who had suffered brain injury to explore how people experienced themselves and their sense of self following significant neuro-trauma and disability. The researchers discovered that during the course of the narrative interviews with their participants, the autobiographical accounts asserted a sense of sameness and continuity for the participants even when they suffered memory impairment. The stories told evoked a sense of continuous self and an unbroken connection between pre injury and post injury self. This study underlines how people are able to attend to the tasks of achieving a sense of personal continuity even in the face of profound changes in everyday life for disabled patients.

Sense of place/dislocation

To be human is to come from a particular place; such a habitat is not just a physical environment measured in quantitative terms but a place where the feeling of at-homeness becomes meaningful. Such a sense of place is not just a collection of colours, textures and objects but rather gathers around that which constitutes the kind of belonging that provides a degree of security, comfort, familiarity, continuity

and unreflective ease. When wrenched away from such a sense of place and locality, one can feel dislocated and one can be made a stranger.

In *dislocation*, a form of dehumanization occurs where a sense of place is lost or obscured and a sense of strangeness arises. In this circumstance people are challenged to find a sense of place in a new and unknown culture where norms and routines are alien to them, and where spatial re-orientation must take place if they are to fit in, similar to "the stranger" who has a sense of dislocation when first experiencing a new place as described in the essay by Schutz (1944).

Insufficient attention is paid to the quality of space in our health care environments. Attention is needed for an architecture of space that can be conducive to privacy, dignity, homeliness and hopefulness. Furthermore, spaces are not just created by the physical environment but by what happens within them and the practices that occur there that make the space hospitable to the richness of human life. The overspecialization of space needs to be tempered by an attentiveness of how to bring forms of life that are fully human to the space. A study by Reed-Danahay (2001) shows how location can be important for a sense of well-being. She carried out an ethnographic study in a residential unit for people with Alzheimer's in the USA using the concepts of place and non-place from Augé and Bourdieu. Analysis showed that some residents experienced greater confusion partly due to the bureaucratic "office-like" and "unhomely" setting in which they lived. In other words, their confusion could not just simply be explained by the neurophysiology of Alzheimer's disease on its own, as if it occurred without a living context. Reed-Danahay thus argues that the biomedical model of Alzheimer patients pathologizes their behaviour and underestimates the human dimensions of living in qualitatively different environments.

In contrast, the following study considers the positive impact that an environment can have, in terms of both its architecture and the practices and routines that take place there. Arman, Rannheim, Rehnsfeldt and Wode (2008) used a phenomenological approach to explore the perspectives of 16 patients who had experienced anthroposophic care at a specialist facility in Sweden. The patients felt that they had encountered an environment that was like a "retreat". The absence of computers, telephones and radio created a "peaceful oasis" that was homely. This study illuminates how well-being cannot be considered separate from the atmosphere and "rhythms" created by the built environment and the ways in which this space "speaks". This anthroposophic hospital referred to in Sweden is a good

example of how a more humanized form of care is supported at many levels including the architectural level. These studies underline how a sense of place is crucial for a more humanizing emphasis when considering healthcare practices.

Embodiment/reductionist view of the body

To be human means to live within the fragile limits of human embodiment. Our insiderness reveals the human body as tiredness, pain, hunger, loss of function, excitement, vitality and other experiences of the human body's being-in-the-world. When un-preoccupied with the vicissitudes of bodily attention, embodiment supports us in moving out into the world, attentive to people, places and tasks in life. Alternatively, one's attention can be dominated by bodily messages that announce "dis-ease" and are a reminder of the limits of our everyday possibilities and potentials. Consistent with this dimension, a humanizing perspective will view well-being as a positive quality that makes life worthwhile and not just as an absence of illness, with the body viewed as merely an object to fix. A model of causality that is deterministic and linear can be de-humanizing in that it underestimates human spirit, purpose and meaning.

In a *reductionist view of the body*, there is an overemphasis upon signs and symptoms and the body as separate from its broader contexts. There is an excessive emphasis on tissue, organ, hormones, electrolytes and a neglect of a more relational view of the body in its broader meaningful context such as psychological, environmental, social, and spiritual matrices. A reductionist causality regarding the body can be dehumanizing in that it can neglect the implications of "being a person in there". A view of biomedical causality that stresses a microanalysis of internal structures can be an overly narrow perspective when describing the complexity of meaningful relationships of living in which the body participates; this oversimplification can reduce ones' more complex sense of embodiment. Conversely, when a person's embodiment is considered within its broadest meaningful relationships, their options for healing resources may be broader, and they may feel more in accord with the complexities of living. The emerging field of "mind body-medicine", although expressed in an excessively dualistic way, is an acknowledgement of the need to consider broader causal contexts in a more comprehensive view of illness and well-being. Likewise, the increasing attention to environmental and complementary medicine similarly expresses an awareness of a broader and alternative framework of intelligibility for wellness. An example of a dehumanizing inter-

action that is informed by a reductionist view of the body is when a professional disbelieves a patient's symptoms because the evidence for their back pain does not "show up" in physical tests.

An empirical study from Canada demonstrates one of the ways in which less reductionistic views of the body can become important in supporting more humanizing forms of care. Kontos and Naglie (2007) used performance-based presentations to help health professionals become more aware of the danger of depersonalisation when patients cannot communicate in verbal ways. Here, a view of the moving body as a realm of significant meaning becomes an important resource for humanizing practices. Based on findings from focus groups with older people with Alzheimer's, they demonstrated how patients' bodily expressions could be understood in more meaningful ways. They showed how, in spite of increasing dementia, patients retained a sense of "embodied selfhood" and how their bodies meaningfully communicated "states of self" without words. By facilitating increased understanding of how patients communicated in bodily ways, professionals could then learn how to respond in interactive ways that confirmed the "personhood" of the individual, even when they could no longer verbally express themselves fully. This is one example, where an understanding of non-reductionist views of the body becomes important as a humanizing resource.

The reciprocal relationship between the humanizing value framework and qualitative research

The eight dimensions offer a framework for distinguishing both the range of humanizing issues that could be fruitfully researched, as well as an evaluative basis from which humanizing and dehumanizing elements can be judged along a spectrum of possibilities.

The range of research programmes would thus include qualitative studies on all features of humanization relevant to the eight dimensions. Therefore, for example, one could imagine an interesting interdisciplinary programme that includes architects and human geographers whereby patients' experiences are analysed in order to support the design of built facilities that are conducive to a sense of well-being and "at homeness". Taking the framework as a whole with its eight dimensions also allows consideration of where research programmes may be particularly needed. For example, one may find that there are many meaningful studies in the area of increasing patients' agency but a lack of studies in another important area such as "sense making"

whereby new understandings of how patients make meaning of their illness and situations can inform professional consultations.

The framework also provides an evaluative basis from which humanizing and dehumanizing elements can be judged along a spectrum of possibilities. Each of the eight dimensions (such as agency/passivity) provides a particular nuance that expresses its potentially humanizing and dehumanizing elements in caring systems and interactions. In practice these extremes very seldom occur. However, it is useful to consider the direction of movement that may be appropriate in any concrete situation. For example, in an intensive care context, Todres et al. (2000) showed that a patient became aware how at a certain stage within the marginality of her situation, it became important for her to value the definition of her well-being in more objectified ways as given by feedback from the monitors around her. She describes a moment where she "felt fine" but realized from the activity of the professionals that her condition was critical. At this stage, she very quickly achieved a switch of perspective in which she fully valued and participated in the more objectified definitions of what was going on. At another stage however she indicated how she really needed the professionals around her to be more flexible in moving into a more humanizing emphasis, which validated and nurtured a sense of her "insiderness" and subjectivity. She became aware of how such flexibility is not often easily achieved. In providing this dimension of insiderness/objectification and research that illuminates such dilemmas, health care professionals might become more sensitive to the human complexities of care in concrete situations.

In conclusion, the framework is thus able to provide a helpful coherent value base for guiding a dedicated and coherent research programme.

Qualitative research: Offering distinctive support to a humanizing emphasis for care

The studies used here to illustrate each of the eight humanizing dimensions, give an indication of how qualitative research is particularly conducive for illuminating the complexity, depth and range of living situations relevant to more humanized forms of care. A humanizing emphasis requires a particular kind of "knowledge for care" and needs studies with certain epistemological and methodological characteristics. Such characteristics are intrinsic to qualitative research and include a focus on the insider perspective, description, evocative impact, rich unique contextualization rather than a premature

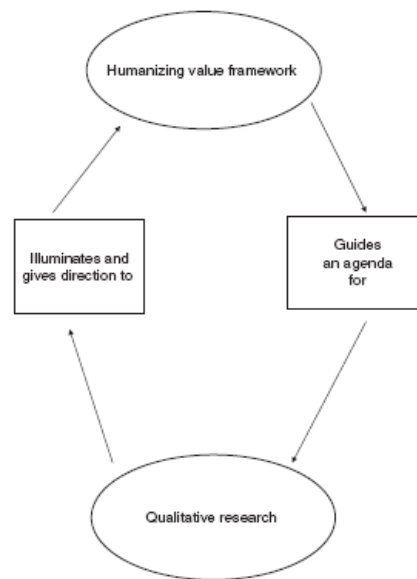


Figure 1. The reciprocal relationship between the humanizing value framework and qualitative research.

emphasis on abstraction, and discovery orientated, open ended enquiry.

We are thus describing a reciprocal relationship between a humanizing framework for care and qualitative research that can be expressed in the above diagram (Figure 1).

Conclusion

Is the humanization of healthcare a luxury? We do not think so. There is increasing evidence in the media, and in our culture at large, that everyday citizens are worried that the more personal dimensions of care are being neglected in favour of "bottom line" outcomes; the quality of the journey is just as important as the destination. So, it is not that humanization of healthcare is not important; clearly it is, as evidenced by recent policy documents that highlight professional compassion, dignity in care and greater patient choice (Department of Health, 2008, *"The Darzi Report"*). Although this policy document is within the British context, it is significant because it explicitly addresses the need to humanize healthcare. However, more than that, as a professional and academic community, we are lagging behind in articulating a coherent qualitative framework for

care. It is in this context that a dedicated focus for developing theoretical frameworks and research studies that support the humanization of care may be timely. If not, existing efforts and pockets of practice that attend to humanization may remain piecemeal as isolated practices without guidance from coherent theories and research programmes.

Do we need a different emphasis on what the distinctive contribution of qualitative research can be? We think so. During the various stages in the development of qualitative research, scholars have been particularly attracted to its core methodological and emic strengths (Morse, 2002). Recently Lincoln and Cannella (2004) have shifted this debate to the level of public policy discourse; they discuss the contribution of qualitative research as a way to uncover "oppressive, inequitable, and unjust social practices" (p. 5), and this can become one of its most distinctive contributions. In line with this, it could be that a different emphasis is needed when championing the value of qualitative research. Our particular emphasis concerns a movement from the methodological contributions of qualitative research to an emphasis on the implications of the findings of qualitative research as a systematic whole for humanizing caring practices. This is unashamedly an ethical pursuit for qualitative research, but we think that it is a pursuit to which qualitative research is particularly well suited. It can be argued that qualitative research is now at an interesting historical point. It is at a stage of development where findings can become more systematized within a value framework and which can serve as a rigorous and credible ground for guiding practice and policy. This achievement reflects how an emic methodological focus has opened up more general insights that have an intrinsically qualitatively human and ethical dimension. It is this qualitatively human and ethical dimension that may be a new phase in articulating the distinctive benefits of qualitative research findings. Moreover, it is in this context that we offer this conceptual framework for humanizing healthcare.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

- Arendt, H. (1963). *Eichmann in Jerusalem: A report on the banality of evil*. London: Faber & Faber.
- Arman, M., Rannheim, A., Rehnfeldt, A., & Wode, K. (2008). Anthroposophic healthcare—different and homelike. *Scandinavian Journal of Caring Sciences*, 22, 357–366.
- Charmaz, K. (2006). Measuring pursuits, marking self: Meaning construction in chronic illness. *International Journal of Qualitative Studies on Health and Well-being*, 1(1), 27–37.
- Charon, R. (2006). The self-telling body. *Narrative Inquiry*, 16(1), 191–200.
- Department of Health (2008). High quality care for all. Next stage: review final report. Retrieved September 5, 2008, from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
- Del Barrio, M., Lacunza, M. M., Armendariz, A. C., Margel, M. A., & Asiain, M. C. (2004). Liver transplant patients: their experience in the intensive care unit: A phenomenological study. *Journal of Clinical Nursing*, 13(8), 967–976.
- Heidegger, M. (1962). *Being and Time*, trans. J. Macquarrie and E. Robinson. Oxford: Blackwell. (Original work published 1927.)
- Holloway, L., Sofaer, B., & Walker, J. (2007). The stigmatisation of people with chronic back pain. *Disability and Rehabilitation*, 29(18), 1456–1464.
- Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology. An introduction to phenomenological philosophy*, trans. D. Carr. Evanston: Northwestern University Press. (Original work published 1936.)
- Johansson, A., & Ekebergh, M. (2006). The meaning of well-being and participation in the process of health and care—women's experiences following a myocardial infarction. *International Journal of Qualitative Studies on Health and Well-being*, 1(2), 100–108.
- Kontos, P.C., & Nagle, G. (2007). Bridging theory and practice: Imagination, the body and person-centred dementia care. *Dementia*, 6(4), 549–569.
- Lincoln, Y. S., & Cannella, G. S. (2004). Qualitative research, power and the radical right. *Qualitative Inquiry*, 10(2), 175–201.
- Medved, M. L., & Brockmeyer, J. (2008). Continuity amid chaos: Neurotrauma, loss of memory, and sense of self. *Qualitative Health Research*, 18(4), 469–479.
- Merleau-Ponty, M. (1964). *The Primacy of Perception*, James Edie (Ed.), Evanston, IL: Northwestern University Press.
- Morse, J. M. (2007). Why humanized health care? Plenary address. Saiyud Niympiphat Lecture at the First Asian International Conference on Humanized Health Care, Khon Kaen, Thailand Dec. 3–5, 2007 (Proceedings pp. 74–81).
- Morse, J. M. (2002). Qualitative health research: Challenges for the 21st Century. *Qualitative Health Research*, 12(1), 116–129.
- Parsons, T. (1951). *The social system*. London: Routledge and Kegan Paul.
- Rasmussen, D. M., & Elverdam, B. (2007). Cancer survivors' experience of time—time disruption and time appropriation. *Journal of Advanced Nursing*, 57(6), 614–622.
- Reed-Danahay, D. (2001). "This is your home now": conceptualising location and dislocation in a dementia unit. *Qualitative Research*, 1(1), 47–63.
- Rosenhan, D. L. (1973). On being sane in insane places. *Science*, 177(70), 250–258.
- Schutz, A. (1944). The stranger: An essay in social psychology. *American Journal of Sociology*, 49(6), 499–507.
- Stockwell, F. (1984). *The unpopular patient*. Beckenham: Croom Helm.
- Todres, L., Galvin, K., & Dahlberg, K. (2007). Lifeworld-led health care: revisiting a humanizing philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, 10(1), 53–63.

- Todres, L., Fulbrook, P., & Albarán, J. (2000). On the receiving end: a hermeneutic phenomenological analysis of a patient's struggle to cope while going through intensive care. *Nursing in Critical Care*, 5(6), 277-287.
- Widäng, I., Fridlund, B., & Mårtensson, J. (2008). Women patients' perceptions of integrity within health care: A phenomenographic study. *Journal of Advanced Nursing*, 61(5), 540-548.
- Williams, A. M., & Irurita, V. F. (2004). Therapeutic and non-therapeutic interpersonal interactions: the patient's perspective. *Journal of Clinical Nursing*, 13(7), 806-815.
-

Appendix No 5: Presentation Slides from the Celebration Day



SSIF funded Dementia Project NHS Somerset

Deborah Gray
Interim Deputy Director, Nursing and Patient Safety
&
Ian Douglass
Head of Service – Older Persons Mental Health and
Learning Disabilities, Somerset Partnership

19th May 2011



SSIF what is it?

- Strategic Service Improvement Fund (SSIF) - previously 'CPD' tagged monies from SHA and allocated to Bournemouth University
- SSIF group included senior representation from healthcare providers in Somerset, and included BU representation

1



- Proportion of monies already committed to existing CPD ,and ringfenced for learning and assessing.
- Need to focus learning monies towards supporting achievement of NHS Somerset strategic objectives
- Agreed three headlines (LTC, Dementia, healthy lifestyles) and took them to SSIF Brainstorming session

2

- Group agreed to move away from traditional models and be innovative in approach to the project
- Consensus to focus on dementia training to complement the launch of the Somerset Dementia Strategy
- Somerset Partnership agreed to go away and work on the ideas discussed in relation to lecture practitioner type resource – November 2009
- Project plan consulted on and approved by SSIF group

3

Dementia Project aims

To develop skills and knowledge of staff in Somerset through a range of programmes to enable better and more effective working with people with dementia.

Programme designed with BU and a Project team developed

Project Plan for one year April 2010- March 2011

4

A Tall Order – Objectives of the project

Provide practical learning and support to staff, work with them to develop practice

Provide sustainable learning opportunities- need for a legacy as one year monies only

Establish a Somerset Dementia collaborative

Develop programmes for staff in supporting patients, families and their carers.

Measure and audit practice to evidence changes supported by BU

5

How we implemented the brief

- Key was the multi agency approach
- Recruitment- project manager and lead professional both one year part time secondments
- Key partners involved in recruitment BU and NHS Somerset
- Established a steering group- membership from all participating agencies
- Develop and monitor workplan to meet aims

6

- Led and owned by acute and community Trusts supported by Somerset Partnership
- Co work with Bournemouth University-evaluate and measure outcomes
- Regular progress review, support and problem solving by the steering group
- Senior Managers fully and actively supporting

7

Key to success

- Champions and frontline staff engaged
- Making it practical- projects and learning
- The approach taken by the Project Manager and Clinical Lead

8

Dementia Project

- Discussion - did we achieve our initial objectives?

9

Dementia Project

- What can we all do to ensure sustainability for this work?


10

Final thank you Kate, Marilyn and Les at BU for your support and assistance

Very big thank you to Jan and Jason for their very hard work and commitment they have both been brilliant !




11



Somerset Collaborative for Dementia Care

April 2010 – March 2011




Older People's Services

Jan Seewooruttun, Project Manager


Jason Weetch, Clinical Lead

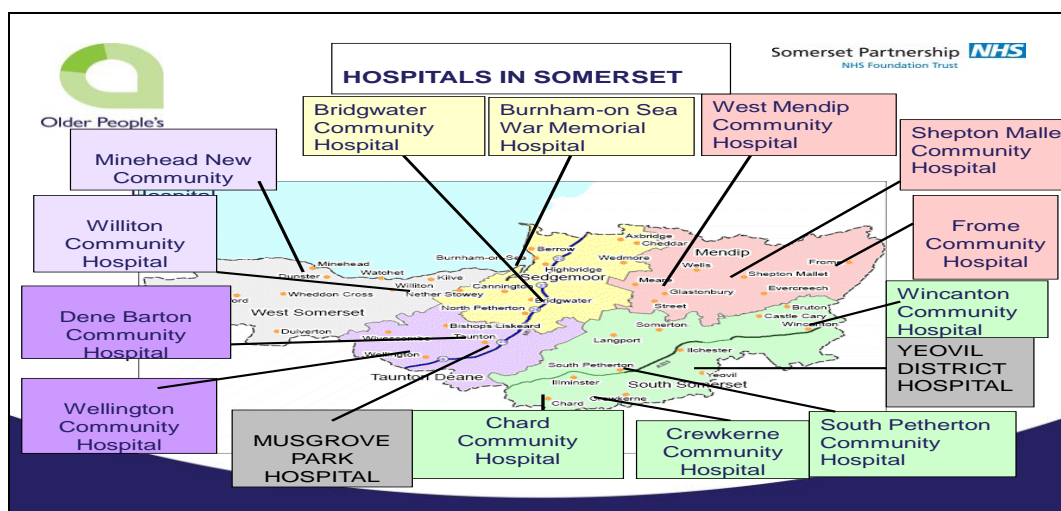
Sue Smith, Carer



Aim of the Project

- **Work with General hospital staff to improve dementia care**
- **Develop a Sustainable Network across Somerset**
- **Work with Bournemouth University to evaluate the project**





What we did

- Decide what was realistic
- Contact Health organisations
- Develop work plan
- Work with University

Our Strategy

- Incorporate Bournemouth Model
- Awareness Raising
- Sustainable Network
- Ward Based Projects

Bournemouth University

**The Humanisation of Healthcare:
a
Person- Centred Approach**

Humanization Framework

- Developed by Professors Kate Galvin and Les Todres
- 8 inter-related dimensions of being human
- Healthcare can reinforce or undermine a person's humanity
- Abstract Model - great explanatory power
- Practical questions

How we used the Model

Agency/Passivity

- Making choices key aspect of being human
- To be rendered passive is dehumanising
- *"How do we ensure that people have a say in their care?"*
- *"How Do we improve this?"*

Uniqueness/Homogenisation

- To be human is to be unique
- Not to be reduced to Category
- Seeing Dementia first is dehumanising
- *"How do we meet people's individual needs in relation to personal care, mealtimes occupation?"*

Awareness Raising

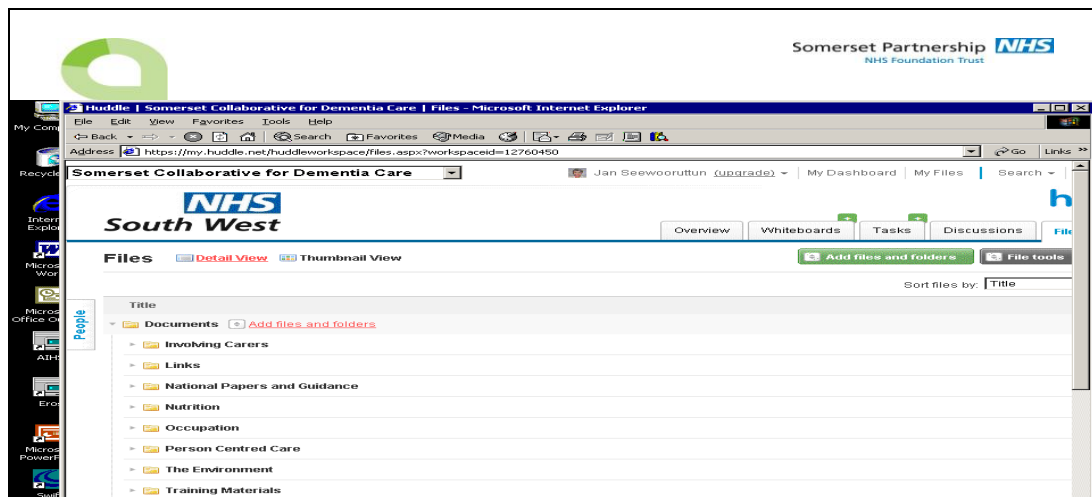
- Design a 1 -1 ½ hour session available to each hospital
- Include Visualisation (Bradford Dementia Group)
- Develop scenarios


Awareness Raising



Sustainable network

- 1332 square miles
- Minehead and Frome
- 13 Community Hospitals
- 2 District Hospitals
- www.Huddle.net

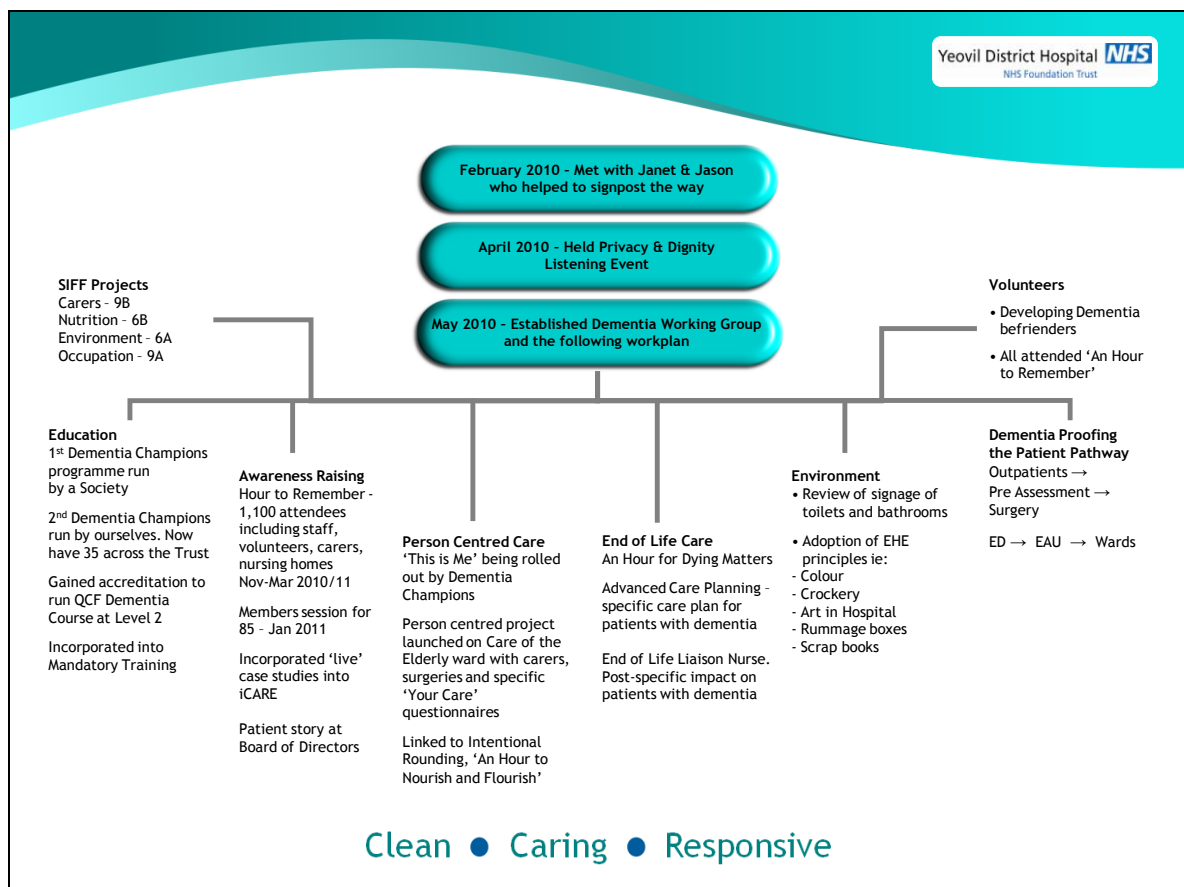




Somerset Partnership **NHS**
NHS Foundation Trust

Ward Based Projects

- Involving Carers
- Environment
- Occupation
- Person Centred Care
- Nutrition
- Use of Antipsychotic medication
- Administration tasks





Evaluating Practice Development in Dementia Care: a humanising values approach

Kate Galvin, Les Todres, Marilyn Cash
Centre for Qualitative Research

www.bournemouth.ac.uk

Introduction

- Collaboration
- Towards humanly sensitive care: a framework
- The evaluation so far

www.bournemouth.ac.uk

Why Humanisation of Healthcare?

- Substantial advances in healthcare, specialisation has improved well-being
BUT
- Human dimensions of care can be obscured
- Humanising values framework to guide research and practice

www.bournemouth.ac.uk

What is humanisation?

- What do we mean when we use the term humanisation?
- What are the barriers to humanisation of healthcare?
- Western context increasingly specialised and technical - a strong emphasis on policies and practices that emphasise audit, control and evidence based practice

www.bournemouth.ac.uk

Dimensions of Humanisation: A values framework

Forms of Humanisation

Insiderness
Agency
Uniqueness
Togetherness
Sense – making
Personal journey
Sense of Place
Embodiment

Forms of Dehumanisation

Objectification
Passivity
Homogenisation
Isolation
Loss of meaning
Loss of personal journey
Dislocation
Reductionist view

www.bournemouth.ac.uk

Humanising Dimensions

- **Insiderness:** Connecting with people's 'inward sense' of how they are, and avoiding making people feel excessively like 'objects'
- **Agency:** Enhancing people's sense of being an active participant in their care and avoiding anything that reduces dignity.
- **Uniqueness:** Practices which help a person feel that they are seen as individuals, not a category or diagnosis.
- **Togetherness:** Practices that address the need for belonging and find familiar interpersonal connections so that any sense of isolation is reduced when facing challenging conditions and treatment.

www.bournemouth.ac.uk

Humanising Dimensions (Cont.)

- **Sense-making:** Ways of communication and information-giving so that people don't just feel like a 'cog in a wheel'
- **Personal journey:** Practices which help people to retain a sense of their own history and continuity
- **Sense of place:** Practices that enhance the physical environment around care so that people can feel more 'at home'
- **Not just a 'body':** Practices that help people to expand their horizons beyond just a definition of themselves in terms of 'passive recipient', 'diagnosis' or 'symptoms'

www.bournemouth.ac.uk

Derived Practical Questions

- **Agency:** What would make you feel that you have more of a say in your engagement with the service?
- **Sense of place:** What would make you feel 'more at home' in the places that you receive service?
- **Sense of journey:** What would make you feel that your 'care' and the way that you are treated is 'joined up' with what has happened with you and the services you have received in the past?
- **Togetherness:** What would make you feel less isolated and more connected with the people who matter to you when you are having services provided by this setting?

www.bournemouth.ac.uk

Evaluation: Early Findings



www.bournemouth.ac.uk

Approach to Education

- Bridged Theory-Practice Gap
- Staff Ownership of Project
- Based in Workplace
- Practical Way of Learning
- Interactive Workshop (Lived Experience)



Benefits of this Approach

- Increased awareness of Dementia
- Enabled people to see the person behind the illness
- Empowered people on the ground to take control and innovate



Lived Experience Workshop

- Makes me understand what a lonely world patients live in'
- 'Allowed me to understand how a patient may feel'
- 'I will give a patient more time to try to make them feel more settled in their unknown environment'
- 'Try and change my practice to put myself into these patients' shoes'
- Has opened my eyes to parts of my practice I could do differently'

Ward Projects

- Involving Carers
- Occupation
- Environmental Changes
- Person Centred Care



www.bournemouth.ac.uk

Challenges

- Staff Time
- Financial Resources
- Hospital Design
- Institutional Barriers
- Culture of Care
 - Person-Centred Care v Task Centred Care
 - Health v Mental Health



www.bournemouth.ac.uk

Conclusion

- Where we are now
- Next steps
- Dissemination Plans



www.bournemouth.ac.uk

**‘The momentum for change
needs to be nurtured and taken
forward, there are -**



**lots of little seeds growing and they need to be
protected and allowed to grow now and that’s a
challenge for all the organizations involved in the
project’** (Interview Participant)