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Operationalizing person-centered dementia care in the acute general hospital

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Summary

Improving the acute hospital care of people with dementia is a priority worldwide.[1] Reports suggest many staff feel unprepared in delivering care, and patients and family carers raise concern over care received.[2],[3]. Introducing 'person-centered care' has been suggested to improve the hospital experience of those with dementia.[4],[5],[2],[6]

We developed and evaluated a Medical and Mental Health Unit (MMHU) as part of a research and development program [7]. The MMHU evolved from a standard acute geriatric medical ward over 18 months prior to evaluation by clinical controlled trial. The MMHU was created to meet the needs of 'confused' older people admitted to the acute hospital by offering acute medical care alongside mental health expertise. Most patients have dementia, with or without delirium. We searched for examples of best practice. We reviewed research and other literature; we visited other services, and a number of senior nurses and researchers received training in person-centered care and dementia care mapping at the University of Bradford's Dementia Studies department.

The purpose of this paper is to describe the application of person-centered care to the acute hospital setting. Following an overview of Kitwood's philosophical approach [8], we focus on the key changes required to support and sustain a person-centered approach to the care of older adults in hospital.

Background

Person-centered care is a philosophy and approach to care developed in nursing homes where residents with dementia were found to be disengaged, in low mood, and often responding to care interactions with fear or aggression. Through extensive ethnographic observation Kitwood described behaviors, mood and engagement, and specific interactions that enhanced or detracted from the 'personhood' of the resident. [8]

Person-centered dementia care calls for respect and value for individuals as the person that they are (their 'personhood'), in a social environment where they experience: comfort, identity, attachment, occupation, and inclusion. These five domains together are identified as key components of retaining (or even rediscovering) personhood.





Kitwood used the term 'malignant social psychology' to describe the way carers could (unintentionally) undermine personhood. For example by: outpacing or intimidating them, treating them like a child, disparaging or blaming them for inadequacies, manipulating/tricking them, invalidating their reality, ignoring or mocking them. He then suggested that 'positive person work' could counteract malignant social psychology. For example by offering: a relaxed pace, warmth, respect as an adult member of society, celebration and recognition of skills and achievements, openness and honesty about what is happening, being inclusive, and having fun. Kitwood proposed an Enriched Model of Dementia. [8] This approach to understanding the person with dementia aims to prevent the condition being considered simply a neurocognitive disorder by emphasising in addition, physical and mental health, biography (life history), personality, and the impact of the social psychological environment.

As dementia progresses the ability for rational, language-based communication diminishes and the ability to express oneself and understand others becomes reliant on emotional cues and feelings; therefore the tone in which words are spoken, caregivers' body language and facial expressions become paramount. Delivering person-centered care cannot only be the provision of good physical care but must also provide for the emotional and psychological needs of the person who is unable to satisfy these needs independently. [7],[9] We recognized many of the same responses in the acute patient population as described by Kitwood. Apathy, withdrawal, low mood, agitation, aggression, and other signs of potential distress such as pacing and repetitive vocalization were common, and staff found these difficult to deal with. In addition, we also have to manage the acute illness or functional crises that resulted in hospital admission, making these patients extremely complex. Hospitalization is in itself a significant stressor and may appear alien and threatening from the perspective of someone with dementia. We aimed to develop a model that mitigated this.

Building a Person-Centered Team Approach to Care

The problem and the evidence: Family carers report that nurses do not recognize or understand dementia, and staff report difficulties in communication and challenging behaviors.[2] Education and training are the starting point to change attitudes,





increase knowledge and skills and change the culture of care. Ideally, educational strategies should engage staff on an emotional level³, including a move away from the perception that the behaviors of people with dementia act as a distraction from their real duties to one where understanding a person's behaviors is integral. [10] This requires putting aside some staff priorities, to consider what is in the best interests of the patient. [11] An infrastructure is required to support, develop and sustain changes in practice. [12]

Our Experience: The interdisciplinary MMHU team was already experienced in acute medical care for older people, yet most were unfamiliar with Kitwood's philosophy, so we devised an education program involving training days, lectures, and experiential learning activities. We began with an exercise designed to help staff explore their feelings and attitudes about dementia and consider how a better service for people with dementia in an acute hospital might look. This allowed staff to raise concerns about the changes on the unit, such as how to manage patients with "difficult" behaviors, communication difficulties, having enough time to spend with patients, and ensuring staff and patient safety. Two further training days were delivered covering more advanced aspects of care including topics such as: communication, speech and language, and meaningful activities.

Workbooks were distributed [5] and education sessions were delivered on topics including: diagnosing dementia, drugs, communication, and function.

As well as imparting new knowledge and skills, the education program helped to foster team spirit and to engender a shared ethos of care. Flexibility in providing education and an experiential approach were key to making these abstract ideas meaningful and applicable to practice.

We were aware of the limitations of classroom-based learning with a reliance on didactic sessions. So we relied heavily on the senior nurses, additional mental health nurses and therapists to support training on the new unit and role model person-centered care. [7] Mental health staff demonstrated new ideas and approaches; both in difficult situations





and more routine care delivery, but also sometimes confirmed that existing approaches were appropriate, increasing staff confidence that they were doing the right thing.

Knowing the person

The problem and the evidence: A key issue in providing person-centered care is that professionals know and understand the individual as a person. [13] For example, knowing the person's preferences or how the person expresses anxiety or unmet needs and what helps them cope. This presents a challenge within acute settings with short lengths of stay, severe time pressures [14], and many professionals working in the same clinical area. [10] It can be difficult for nurses to establish a bond [15] and this can be upsetting for the person with dementia. [16] The person with dementia needs to be assisted to settle into the unfamiliar environment. [17] Personal belongings can help with this by providing a sense of place. [10]

The nurse needs to acquire information about the person so that they are equipped to initiate conversations, activities or routines that will promote a sense of self and normality [13] and encourage staff to respect the person they are caring for. [18], [13]

It is important to gain understanding with both the physical and psychosocial needs of the person, including how they are affected by dementia [19], and their life history. [15] Berg et al [20] found that nurses could place behavior in the context of earlier life experience, culture and social status, and this helped them reach a judgement as to whether or not particular behavior patterns were the norm for the individual or if they were expressions of particular distress.

Our Experience: On the MMHU, a personal profile document 'About Me' was developed and adapted from existing documents. [21] Relatives are asked to complete it on admission and it is kept at the end of each patient's bed. As well as providing biographical detail, it provides information which helps staff to recognize and act on individuals' responses to stress or pain.

The process of understanding the person with dementia is further enhanced by personalizing the patient's area. Relatives are asked to bring in the person's usual day





clothes and to provide familiar items, such as a blanket or keepsakes and photographs, which can be kept in a wall mounted “memory box” behind each patient’s bed. This has had a mixed reception with family carers and only a few have participated.

Some staff received training in the use of ‘Talking Mats’ supported communication system (a visual aid to communicating thoughts and feelings) [22], although in practice this has not been much used. Dedicated speech and language therapy time has supported adaptation of communication styles to help better engage the patients and gain their preferences. A relaxed pace is adopted, simple choices are offered, only one question is presented at a time, and more time is given for responses.

The importance of communication in implementing person-centered care extends to how we talk about patients. The use of labelling people (for example, as a bed space “green three” or by their behavior, as a “wanderer”) is avoided, and the goal is for behaviors to be described in a structured way with emphasis on antecedence, behavior and consequence.

Purpose and activity

The problem and the evidence: Nurses must find a balance between under and over-stimulating people with dementia. [16]. Lack of stimulation, can lead to increased restlessness or agitation and loss of skills related to activities of daily living. However, an environment containing numerous, competing stimuli can be more distressing. The literature emphasises ‘meaningful activity’ [23], [13]– providing some kind of stimulation that appears to have personal relevance to the person with dementia. This can be achieved by providing pleasurable activities [23], by making routine activities individually meaningful [13] and by facilitating or providing moments of ‘togetherness’ between the person and a staff member, friend or relative. [20] Particular attention is paid to ensuring that activities are graded to complement rather than exceed the individual’s capabilities, for example using occupational profiling. [24]

Our Experience: On the MMHU, strategies have been put in place to try to achieve all three approaches to providing appropriate stimulation for people with dementia. For those well enough to attend, there is communal dining and a structured activity





program is in place, supported by activity coordinators (health care assistants) under the supervision of an occupational therapist. The goal of these activities is not only to provide occupation but also a sense of inclusion and belonging.

A similar approach is promoted when assisting with personal care. Nurses are encouraged to facilitate the patient doing for themselves through collaboration and verbal encouragement, rather than to achieve the outcome in as little time as possible. For patients who are able to engage with activities at a simpler sensory or reflex level, nurses have been taught to enhance the experience by emphasising the sensory aspects (warm water, the smell of soap etc.). This encourages staff to consider all activities as opportunities for patients to maintain skills, as well as maintaining a sense of self-worth and purpose.

Meaningful moments are facilitated by promoting the involvement of relatives in supporting the person with dementia. In addition, staff members have developed a more spontaneous way of interacting that capitalizes on moments of happiness and good spirits, for example by making eye contact and smiling or stopping to sing or dance with a patient.

Engaging with carers

The problem and the evidence: Caring for people with dementia, inevitably involves their relatives and friends. The literature which considers the relationships between health care professionals and family carers of people with dementia is ambiguous. The benefits of a close working relationship between health professionals and family carers are clearly identified. [19], [13], [25] However, family carers may have different perspectives and needs from the person with dementia, [10] and there is scope for disagreement or conflict between health professionals and family carers. [16], [26] It is not feasible for family members to be on the unit at all times, and they may want to know what is happening to their relative when they are not there. [17], [15] However, there may be times when professionals believe that they have to protect the person with dementia when they believe that the family carer is not acting in their best interest. [10], [15]





The benefits of a good working relationship between health care professionals and family carers are clear: family carers often have a detailed knowledge of the person with dementia and can provide useful information about their specific nursing needs. [15], [13] In addition, the family carer might want to be involved in the supporting the person with dementia while in hospital, maintaining continuity and routine, encouraging emotional calm, and reducing insecurity. [16] However, being a family carer of somebody with dementia can be demanding physically and emotionally [19] and family carers might view hospital admission as a time of 'respite', [10] so the family carer may not want to be involved in supporting the person with dementia while in hospital. [15]

Our experience: We were aware of the potential difficulties in relationships between professionals and family carers. In particular, members of staff were wary of relatives' questions, fearing criticism or time wasting. Yet from a person-centered perspective, relatives would know the person with dementia best. Staff members on the MMHU were encouraged to engage with family carers often, but to gain information quickly, family carers are asked to complete two documents: the 'About Me' tool and another document 'Caring Together'. Caring Together asks the carer how they are normally involved in care, if they would like to continue doing so while their relative is in hospital (e.g. helping with meals/ helping them to wash), whether they like to be contacted if their relative needs them (e.g. they are distressed at night), and how best to communicate with them. In addition, this document portrays the unit philosophy - that the staff members on the ward are proactive in seeking carer involvement, recognize their expertise, welcome their input, and are happy to share caring responsibilities.

Creating a "dementia-friendly" environment

The problem and the evidence: An important task facing the new unit was to overcome the environmental problems that face a person with dementia in a typical hospital ward. We have described physical changes made elsewhere. [7] Important here was the management and identification of patients' space. Nurses and patients perceive the ward differently: one as a 'work space', the other as a 'living space' to be explored. This leads to behaviors, such as walking, being seen as problematic and inappropriate by nurses.





[27] Furthermore, patients who are prone to aggression require a larger personal space than others. [16]

Our Experience: Behaviors that may be expressions of distress, such as exit seeking, agitation and pacing, are often encountered on the patient's arrival to the unit when they are most frightened and disorientated. Staff learned to recognize that the way they interact with the person will have a direct effect on these behaviors. Rather than seeking to contain or confront these behaviors, they are monitored without intervention, while staff members seek to respond to the emotions by offering reassurance, comfort or redirection. We have attempted to accommodate behaviors which might be seen as unacceptable whenever it is safe to do so.

Unique challenges are presented in trying to accommodate such behaviors in a communal and clinical space, while also trying to maintain the safety and dignity of the individual and others. Digital locks have been installed to prevent access to unsafe areas, fire extinguishers have been boxed in, and patient lockers have been fitted with a lockable drawer, so items can be locked away. If required, nurses guide people away from areas they do not wish them to enter, for example into another patient's bed area when care is being given, but they avoid chastising them.

Corridors are kept free of unnecessary items to provide space for those wishing to walk up and down and frequent resting places are provided. There is an alcove with seating, which provides a quieter area for those seeking solitude. A small interview room was fitted as a sensory room with projected images, music and fibre optics to aid relaxation or diversion. At the end of each bay are small tables and chairs, providing not only an additional resting place but also an impromptu place to eat or sit and chat. These areas allow staff to be more flexible (for example when writing notes), respond to the individuals needs and have more opportunities to engage them in activity. Bay areas are decorated in distinctive colors, clocks and orientation boards are prominent, and pictorial signs are used for toilets.

Creating personal space continues to be difficult in acute care settings; we remain a 28 bedded unit in a traditional design, within an average ward space.





Ward routine

The problem and the evidence: Cowdell noted that task-orientated nursing involved routine taking priority over the needs of patients. [3] Family carers of the person with dementia want staff members that are available and not distracted by tasks that are not 'person-centered'. [13] High activity times of the day can increase distress behavior, suggesting staff should be flexible planning tasks for times of lower activity. [16] However, some aspects of ward routine can promote person-centered care, such as mealtimes in a dining room which creates a sense of 'belonging', and help orientates to time of day. [28]

Our experience: Staff on the MMHU maintained a general routine (including mealtimes, medicine rounds, and handovers) to ensure efficiency with the provision of medical care. However, a more flexible approach has been supported; to be increasingly person-centered in the way they deliver the routine. Patients and families are asked about aspects of the day or night time routine that might be especially important. Staff are more flexible with tasks, for example, if having a shower causes distress despite staff attempts at relaxed collaboration, then the task will be stopped and attempted again later. Other aspects of the hospital routine are less flexible, such as the times that meals are served or when investigations are performed. Even then, we have found ways to adapt, such as providing snack boxes when a patient requests food or shows signs of being hungry, regardless of when they last ate.

Patient Safety

The problem and the evidence: Borbasai et al [10] discuss the problems staff in hospitals face in maintaining the safety of patients with dementia describing the need for increased supervision and attention, but lacking the resources to meet these needs resulting in the use of restraints. The use of sedative medication has also been questioned, and measures to reduce antipsychotic prescription urged. [29]

Distress behavior should be seen as an expression of feelings or unmet needs.





Assessment should try to understand and address these feelings, sometimes called 'clue finding' and 'motive identifying'. [30]

Our experience: The important issues on the MMHU were risk of falling, infection control, aspiration due to neurogenic dysphagia, interference or aggression from other patients, and supervision for those expressing distress behaviors.

In line with UK policy and practice, staff on the MMHU rarely, if ever, use physical restraint. Psychotropic medication is used judiciously, and only prescribed following a mental health nursing and medical assessment and completion of a care plan. Instead, organizational measures have been taken, including one-to-one supervision. Another strategy is to 'cohort' patients into an area (bay) so that one member staff can maintain constant observation. These strategies do require extra staffing, and this has caused a resource problem that has to be negotiated on a case-by-case basis.

On occasion it was necessary to consider the overall needs of the ward as a whole, and where it was felt that safety may be compromised or a therapeutic environment could no longer be maintained, admissions to the ward were controlled in the short term ('casemix regulation'). This involved discussion with senior hospital management and an informal risk assessment for those new patients coming to the ward to ensure their needs could be met.

When patients on the MMHU experience distress during medical intervention, a flexible and person-centered approach is adapted. However, when the intervention is essential e.g. oxygen or intravenous therapy, a person-centered approach can be compromised by the need to deliver interventions deemed to be "best interest". On occasions a formal assessment of a persons' decision making capacity was required. More often, when considering what is in a person's best interests, a constant, informal, risk assessment process was on-going for each patient. A pragmatic and balanced approach to risk was required, especially in regard to issues such as falls, where the risk can be reduced but not eliminated. A balance must be struck between ensuring patient safety, offering choice, and emphasising a persons' abilities rather than their dependency.





Implications for Practice

The culture of care in most acute settings takes little account of the needs of people with dementia, being considered low priority and taking nurses away from delivering acute medical or surgical care. [11], [25] Nurse interactions with patients with dementia are often limited to meeting their physical needs. [28] However, nurses' interpersonal skills and knowledge are crucial to creating a culture of person-centered care. [12] Changing culture requires a shift in the attitudes, roles, and perspective that can only be sustained by support at an organizational level. [12] Our experience supports that it is possible to provide person-centered care in the acute hospital, but success requires three elements: committed leadership, staff with an understanding of the needs of people with dementia, and adequate resources.

Senior nursing and medical staff were committed to enhancing care delivered on the MMHU and acted as advocates for person-centered care. They had advanced dementia training and were able to challenge poor practice. Senior staff members were able to 'legitimize' delivery of emotional and psychological care (often involving sitting with, or talking to, patients) and were able to demonstrate that a person-centered approach can be embedded into the unit culture without compromising the delivery of acute medical care.

At an organizational level, acute hospitals need to consider how they are going to organize the care of people with dementia. If they are to identify clinical areas that are to develop 'expertise' in working with people with dementia, it is necessary to resource them adequately. Nursing people with dementia takes time - care is slower, there are additional tasks such as: talking to family carers, meeting the needs of those who are distressed, dealing with high levels of physical dependency [31], and ensuring safety. Organizational issues such as the tendency to transfer patients within the hospital [14], the need for continuity of staff, [16] and ensuring staff are on duty at the right time [10] must also be considered.

The experience of staff on the MMHU has been that even when these strong structures are in place, achieving person-centered care in the acute setting has its challenges. The





realities of a busy hospital cannot be completely eliminated – the impact of shift working on continuity of care; patient transfers; the need for equipment and devices; routine physiological observation; short length of stay and ever changing patient mix; sometimes rapid fluctuation in patients physical and mental status; interruptions and over-stimulation. The traditional medical model has its limits but cannot be entirely ignored in pursuit of person-centered care. This is because the reasons a person with dementia is admitted to hospital (usually a physical illness) must be prioritized. Equally, there are times when hospital policy (such as infection control) might be in direct conflict with a person-centered approach.

The MMHU has been successful in delivering acute care in a more person-centered way, but the experience has revealed a limitation of the person-centered model, which is that it was not developed with the hospital in mind. It has been successfully applied within nursing homes where people with dementia live for the medium to long term, but hospital nursing will always be focused on caring for people with dementia for as brief a time as possible, dictated by their medical needs. It has taken considerable investment of time and resources of experienced staff to embed the person-centered philosophy on the MMHU, and applying it across a hospital system would require much more. In fact, our work on the MMHU raises questions about the purpose of mental health care in acute hospital and what care people should expect when they are within its system. In care homes person-centered care is about improving lived experience, despite the restrictions imposed by dementia. In acute hospitals, it may be more to do with minimizing distress and damage caused by loss of familiarity and routine during a period of physical ill health.

Conclusion

From the experience of nursing on the MMHU, we offer guidance on how to work towards best practice in meeting the needs of 'confused' older people in an acute setting. We suggest feasible changes to hospital care that demonstrate previous recommendations can be made to work. However, there are no quick fixes – good dementia care is skilled and labor intensive. It requires enthusiasm from a well-resourced team whose culture of care has become more flexible. This requires committed leadership at the ward and





organizational level, informing health policy and the commissioning of services, which place high value on the person with dementia and the willingness to devote resources to meeting their special needs.

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