# Care of Older People with Cognitive Impairment in General Hospitals

John Gladman,[1] Davina Porock,[1] Amanda Griffiths,[1] Philip Clissett,[1] Rowan H Harwood,[1] Alec Knight,[1] Fiona Jurgens,[1] Robert Jones,[1] Justine Schneider,[1] and Fiona Kearney [1]

[1] University of Nottingham

**Address for correspondence:**

Professor John Gladman
B99a, Division of Rehabilitation and Ageing
B Floor Medical School
Queen's Medical Centre
Nottingham
NG7 2UH
United Kingdom

Email: John.Gladman@nottingham.ac.uk

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# *Executive Summary*

## Background

Mental health problems are common in acute hospitals. In a typical district general hospital with 500 beds, 330 beds will be occupied by older people and 220 will have a mental disorder. Dementia is the most common of these conditions (31% of all older people in hospital). Delirium is also common (20%) and frequently co-exists with dementia. Outcomes for patients with cognitive impairment are worse than for older people in hospital without cognitive impairment, and there are widespread concerns about the quality of care they receive. The care of such people needs to be improved.

## Aims

- To elicit staff and organisational attitudes to dealing with older patients with cognitive impairment

- To elicit staff concerns about their training and competence in this area and suggestions for organisational change to improve care

- To understand the effect of hospitalisation on older adults with cognitive impairment, their carers, co-patients and staff

- To identify potential improvements in this process.

## Methods

Two linked empirical research studies were undertaken.

An interview study was conducted of general hospital staff's confidence, competence and training and of the organisational factors affecting their ability to provide care for patients with cognitive impairment. The sampling frame was 11 acute hospital wards representing acute medical, geriatric and orthopaedic specialties. Sixty staff interviews were conducted across specialties and professional disciplines.

An observational and interview study was conducted of patients with co-morbid cognitive impairment, their carers and co-patients. This study used non-participant observation in the hospital setting and interviewing after discharge at the patient's home. An ethnographic approach, taking the perspective of the patient was used. Seventy two hours of non-participant observations of care were performed on the 11 study wards. Thirty-five

interviews in 34 patients with mental health problems and their carers were conducted. Four co-patients without mental health problems who had shared the ward with a study patient were also interviewed after discharge.

# Results

The staff study found four super ordinate themes:

- Staff perceptions of patient group characteristics
- The challenges and impact on them of working with this patient group
- The ward environment
- Organisational factors affecting staff.

Interpretation of these findings found two key deficits:

- Lack of education and practical training to recognise and manage complex older patients with confusion.
- Inflexibility of a system that imposed unrealistic targets on those caring for such patients and detracted from their time and ability to provide appropriate care.

The observation and interview study elaborated a "core problem" and a "core process". The core problem was that admission to hospital of a confused older person was a disruption from normal routine for patients, their carers, staff and co-patients. The core process described was that patient, carer, staff and co-patient behaviours were often attempts to gain or give control to deal with the disruption (the core problem). Attempts to gain or give control could lead to good or poor outcomes for patients and their carers. Poor patient and carer outcomes were associated with staff not recognising the cognitive impairment which precipitated or complicated the admission and to diagnose its cause, and staff not recognising the importance of the relationship between the patient and their family carer. Better patient and carer outcomes were associated with a person-centred approach and early attention to good communication with carers.

# Conclusions

A hospital admission of a person with cognitive impairment represents a disruption to normal routine to them, their carers, staff and cognitively intact patients sharing a ward with the confused patient. The behaviours that all parties engage in can be interpreted as attempts to regain or give control in response to this disruption. Some attempts to gain control are successful and are associated with good outcomes for patients and carers, but some are associated with poor outcomes.

Hospital staff, from all professional groups and at all levels of seniority, feel ill-prepared to understand this process. Indeed, despite older people with cognitive impairment due to dementia and delirium representing a core population within general hospitals, delivering appropriate care to them often seems to represent a disruption to core business. Many staff recognise that the care provided is not of high quality but do not know what they can do to improve things. Staff cite lack of adequate training as a problem, and that environments and systems are not configured in ways that are conducive to the care of older people with cognitive impairment. Staff express frustration and exhaustion as a result of dealing with disruptive patients within an ill-equipped system.

Our findings are likely to explain and understand how dissatisfaction with the hospital care of older people with cognitive impairment arises, and points towards how it can be improved. We propose that changes are necessary to recognise that care of older people with cognitive impairment is core business of general hospitals. This represents nothing less than a culture shift. Failure to do so will perpetuate poor outcomes and negative experiences of hospital care for patients and carers, and will fail to support staff properly.

All staff groups regularly caring for older patients, irrespective of their specialty and seniority, should be trained to meet the needs of these patients and the other parties affected by their admission. *A guide to training the social care and health workforce (1)* elaborates these key training points. It details 8 core principles inherent to high quality care for older adults with dementia regarding early identification of signs; timely diagnosis; good communication; promoting independence; recognising distress; valuing patient-carer relationships; staff training; and multidisciplinary teamwork. Identifying and correcting deficiencies in the current system in the context of these principles will enable organisations to improve care delivery.

Workplace-based training may be the most feasible and acceptable way to deliver such training, not least to allow staff to reflect on the degree to which they are disrupted and how they respond to this disruption. Prevention and management of aggressive behaviour is a core feature of training for staff in the mental health sector and this training should be replicated for staff in general hospital settings. New practices should arise from such training, and may include routine discussions with carers of patients, to ascertain patient-specific information that will enhance the hospital process and experience for all parties. This information may allow staff to reduce challenging behaviour and other problems, and may also help reduce excessive lengths of stay by improving decision making and the chances of successful discharge home.

More explicit support for carers and encouragement for them to contribute to patient care may help improve patients' safety and nutrition, relieve patient boredom, ameliorate co-patient concerns and help reduce demands

upon nursing staff. The timing and duration of visiting times should be re-considered. Hospitality and accommodation for carers should be available.

Since older adults with mental health problems are cared for on all wards in most departments of general hospitals, provision of information for co-patients and visitors may promote understanding and empathy.

Staff support mechanisms, as would be routine in mental health settings, should be established to help prevent staff burnout and long-term stress from untoward events such as episodes of violence.

Hospital environments need to be designed and renovated with the needs of cognitively impaired older people and their carers in mind. In the physical environment, examples might include improved signage and visual contrast, and more explicit removal of hazards such as storing bins for used hypodermic syringes in locked areas. Activity areas could be protected and made suitable for use by patients and their carers. More volunteers and activities coordinators are needed to facilitate activities.

Hospital processes and organisation also need to be changed. Frequent moves of older people with cognitive impairment should be avoided as they will cause further disruption. Ward nursing staff establishments need to take account of the emotional and psychological needs of the patients. The more patients with cognitive impairment there are on a ward the more time and effort will be required to deal with them. Failure to recognise this represents failure of the organisation to respond to a core need.

The National Dementia Strategy in England has called for the commissioning of liaison psychiatry services. These could potentially provide resources and leadership for ongoing workplace-based education and facilitate changes in the structure and process of acute hospitals.

General hospitals could develop a specialist ward for older people with cognitive impairment which could not only provide care for the most difficult management problems, but serve as a resource for workplace-based training and a hub for development of an expert workforce.

Since care of older people with cognitive impairment is core business, provision of a liaison service or a specialist unit alone should not be seen as a sufficient response by a general hospital. Education and changes to practice are needed wherever patients with co-morbid cognitive impairment are managed, including surgical and specialist medical wards. This requires high level organisational leadership and investment in the care for this patient group.

Further research should evaluate interventions such as: hospital at home; liaison old age psychiatry services; specialist units for delirium and dementia; interventions to improve staff competence and confidence in their competence; interventions for wandering or sleeplessness; innovations in the design of the physical environment; and systematic engagement of family carers.

Concerted efforts are required to avoid a vicious spiral of poor care and replace it with a virtuous cycle of high quality patient-centred care, with well-trained staff, good communication, a suitable environment and an engaged organisation at its core.

# *The Report*

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# 1 BACKGROUND

## *1.1 Introduction*

Mental health problems in older people in general hospitals are common. Anxiety, or worry, is almost ubiquitous. Depressive symptoms and unhappiness are likely also to be very common. Older patients with cognitive impairment (due to dementia, delirium or both) as well as their physical health problems are particularly vulnerable, and have poorer outcomes than people with physical complaints alone. The quality of care for people with co-morbid cognitive impairment can be poor.  Care may be poor because of inadequate staff training and supervision, unsuitable physical environments, poor policies, or a lack of governance and regulation. Studies of the experiences of people with cognitive impairment and their carers, and exploring staff experiences of attitudes towards providing such care are required.

## *1.2 Epidemiology*

The evidence has been reviewed in *Who Cares, Wins* prepared by the Royal Collage of Psychiatrists (2). Older people occupy 2/3 of NHS beds, and 60% of those admitted have or develop a co-morbid mental disorder. Dementia is the most common psychiatric condition in older people in hospital (31%), followed by depression (29%), and delirium (20%) (2).

In *Who Cares, Wins* it was estimated that in an average day in a typical district general hospital with 500 beds: 330 beds will be occupied by older people, 220 will have a mental disorder; 96 will have depression; 66 will have delirium; 102 will have dementia; and 23 will have other major mental health problems (2).

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## 1.3 Quality of care for people with cognitive impairment

There has been a long history of concern about the quality of care in UK hospitals. The media often reports concerns over many basic aspects of care such as feeding, washing and maintenance of dignity (3)

Counting the Cost (4), a report by the Alzheimer's Society, strongly criticised the quality of hospital care for people with dementia in particular.

## 1.4 Factors affecting quality of care for people with cognitive impairment

### 1.4.1 Staff training

The majority of day to day care as experienced by patients and as witnessed by their relatives is provided by nursing staff and health care assistants. One possible reason for poor quality of care for people with cognitive impairment in hospital is that staff are not adequately trained. The origins of this may lie deep in staff training, for example, the most common nursing model of care in the UK since the 1980's is probably that of Roper Logan and Tierney (5). This model is based around the assessment and management of twelve aspects of daily living: maintaining a safe environment; communication, breathing; eating and drinking, elimination; washing and dressing; controlling temperature; mobilization; working and playing; expressing sexuality; sleeping; and death and dying. The emphasis of this model of care is upon activities. Cognition is not one of the core areas of interest, nor does the model focus explicitly upon relationships, understanding behaviour from the patient's perspective or recognizing the impact of their cognitive deficits. Thus the model implicitly focuses attention on physical matters and away from mental ones.

Given the high prevalence of dementia and delirium in older people admitted to general hospitals, one would expect medical students and hospital doctors to be well prepared for the care of such people. Topics such as dementia and delirium are routinely included in undergraduate medical curriculums but workplace–based training for doctors is inadequate (6, 7).

### 1.4.2 Environment

Another reason why the care of older people in general hospital might be poor is due to an unsuitable physical environment. Much research has been undertaken in long term care settings to examine the relationship between

the environment and the quality of care and experience of people with dementia, which we have reviewed elsewhere (8).

Little research has been done in acute care settings but many of the lessons learned in long term care settings may apply in general hospitals. Aspects of the environment to which benefits have been attributed include those that:

- Give rise to a non-institutional character

- Encourage positive sensory stimulation but prevent inappropriate sensory over-stimulation.

- Provide adequate lighting and visual contrast, particularly for those with co-existing visual deficits.

- Facilitate orientation through improved signage or design features that enable better surveillance or short corridors and simple decision points.

- Promote familiarity with the use of personally significant memorabilia

- Provide outdoor areas. Aggressive behaviour and sleep disturbance are reduced where there is access to the outdoors.

If the need to care for older people with dementia  in general hospitals is not recognised, then general hospitals will not be built or furnished with these design principles in mind.

### 1.4.3 Organisational policy

There are many policy documents relating to the care of people in hospital, some of which specifically refer to those with mental health problems. The National Service Framework for Older People (9) comprised 8 "standards" or areas of activity including mental health (standard 7) and the care of people in hospital (standard 4). There are also several other reports and policy documents related more specifically to dementia and mental health published over the last decade (2, 10-18). The last of these, *Living Well, a National Dementia Strategy* (18), devoted a section to the management of people with dementia in general hospitals, calling for clear leadership, the development of clinical pathways, and the commissioning of old age psychiatry liaison services.

### 1.4.4 Governance and regulation

The NHS has generic quality enhancement processes that could be harnessed to improve the care of older people with cognitive impairment in general hospitals. Failure to target governance mechanisms of services could be another factor explaining the concerns over the quality of care for

cognitively impaired older people. An example of a generic process in NHS hospitals is a benchmarking process known as the *Essence of Care*, promulgated by the NHS Modernization Agency (19). This comprises eight inter-related "client-focussed" benchmarks, one of which is "Benchmarks for safety of clients with mental health needs in acute mental health and general hospital settings". This benchmark is focussed on risk management and appears to be designed mainly for acute mental health units and younger patients with mental health problems. It does not address explicitly the special problems of older people with disability, sensory loss or cognitive impairment. Being a governance tool, it is heavily focussed on assessment of risk of harm (perhaps with suicide or violence in mind) rather than, for example, the risk of distress or more subtle concepts such as quality of experience.

Another NHS tool, the *Productive Ward* (20), is a self-directed learning programme from the NHS Institute for Innovation and Improvement, which has had wide uptake throughout the NHS. The version for general wards focuses mainly upon promoting efficiencies to allow "time to care". This could be helpful if lack of time, rather than inadequate training or processes, is a barrier to the delivery of good care.

In relation to legal or regulatory approaches which could be used to improve care, the Mental Capacity Act 2005 (21) specifies how capacity should be assessed, and how decisions should be made in a person's best interests when capacity is lacking. This provides a legal framework for the management of people with dementia who do not have the capacity to complain about poor care or to assert their needs. However, formal assessments of mental capacity are not made routinely in the UK's health system, nor are the principles of the Act widely implemented.

The Care Quality Commission (CQC) (22) is the independent regulator of health and social care in England. The CQC has recently focused attention towards the care of older people, and has published the first of its reports into dignity and nutrition for older people in hospitals in the UK (23). Increasingly the CQC could play a role in influencing the quality of care for older people with cognitive impairment in hospitals.

A further regulatory means through which hospitals in England could be subject to legal sanctions is from local authority Health Overview and Scrutiny Committees (24). These have powers to demand changes in hospitals if they are believed to be unsatisfactory.

## 1.5     *Person-centred and relationship-centred care*

Another limitation to making progress in this area is the understanding of what actually is good or poor care, including the attitudes behind such understanding. The stigma associated with mental health conditions might encourage staff and institutions to ignore them or marginalise those affected. Negative attitudes towards mental health problems might lead

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staff to blame the people affected. Aggressive behaviour might be interpreted as a character flaw to be punished, or it may simply (but erroneously) be seen as an inevitable consequence of such conditions. Failure to eat may be interpreted as wilfulness, failure to remember instructions may be interpreted as stupidity, and so on.

Expert psychiatric care for people with dementia has been considered in the scientific literature, and developed in specialist psychiatric, care home and community settings. The concepts of person-centred dementia care and the preservation of personhood in dementia are pervasive and dominant. 'Personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (25). It is argued that personhood is of central importance in the lives of people with dementia, and its loss represents the tragedy of the condition. It can be maintained in people with dementia by specific actions and approaches, but it can be diminished by society and individuals, including health and social services, particularly when value is attached to functions (such as cognitive capacity), or activities (such as those that maintain economic or physical independence) rather than valuing a person in a relationship and as a social being. The features of what is termed a "malignant social psychology" that does not respect personhood include:

- treachery or deceit
- disempowerment
- infantilisation
- intimidation
- labelling
- stigmatisation
- outpacing
- invalidation
- banishment
- objectification

Central to avoiding these negative effects, and to the preservation and respect of personhood is a person-centred approach. The malignant features of services could helpfully explain the negative attitudes displayed in hospitals, and the insights of person centred care could be used to critique the quality of care. The concept of person centred care has been further refined by the development of the notions of 'relationship-centred care' (26).  Relationship-focussed approaches emphasise the importance of relationships in maintaining or losing personhood – in particular the network

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of relationships between the person with dementia, their families, and health care professionals.

## *1.6 Research questions*

This introduction has outlined that co-morbid cognitive impairment in older people in hospital is common and associated with poor outcomes and high resource use. The quality of care received by these people is a matter of concern to the public and to policymakers. To provide information to enable general hospitals to deliver better care for older people with cognitive impairment , a deeper understanding is needed of how general hospital care is experienced, explaining how the staff and institution affect it, both positively and negatively. Accordingly, the specific research questions to be answered in this project were:

- What are general hospitals' staff's concerns and anxieties about dealing with older patients with cognitive impairment and confidence in their own competence to deal with such patients?

- What is the prevailing organisational culture (hospital and ward level) regarding older people and what are the organisational systems and management practices for older people with cognitive impairment?

- What are staff's suggestions for systems-level improvements to service delivery and for personal/professional development?

- What are the effects of cognitive impairment in older patients in general hospitals upon the care delivered and the outcomes of that care as perceived by the patients, their families, caregivers and advocates, ward staff, and co-patients (other inpatients without cognitive impairment)?

- What would improve the experience of hospitalisation from these perspectives?

To answer these questions the following empirical research was undertaken:

- An interview study of general hospital staff's confidence, competence and training and of the organisational and system factors that affect their ability to provide care for older people with cognitive impairment and

- An observational and interview studies of patients in general hospital with cognitive impairment , their carers and advocates, and the staff looking after them

## *1.7 Structure of report*

In this chapter the nature of the problem was set out and a theoretical framework to help understand and evaluate the findings offered. In Chapter 2, two literature reviews that preface this research are described: a review

of studies pertaining to staff that have most relevance to the care of older people with cognitive impairment in general hospitals, and a review of the literature examining the experience of older people with cognitive impairment in general hospitals. In Chapter 3, the research methods used for the empirical studies are described. In Chapter 4, the results of the staff studies are given. The results of the observation and interviews studies are given in Chapter 5. Chapter 6 discusses the implications of these findings.

# 2 LITERATURE REVIEWS

## 2.1 Introduction to chapter

This chapter presents two focussed literature reviews that preface the research findings. The first is a review of the staff studies of most relevance to the care of older people with cognitive impairment in general hospitals. The second gives the findings of a review of research studies that specifically examined the experience of older people with dementia in general hospitals.

## 2.2 Review of staff and organisational factors

### 2.2.1 Introduction

A brief summary of current knowledge surrounding work and organisational factors affecting healthcare staff in general hospitals caring for cognitively impaired older patients is given here. A critical review approach was taken in view of the diversity of the topic areas, focussing on dementia.

### 2.2.2 Method

**Search strategy**

The following databases were searched: PsycINFO, Ovid MEDLINE(R), Global Health Archive, EMBASE, British Nursing Index and Archive, Allied and Complementary Medicine, SPORTDiscus, CINAHL, and Web of Science. Search terms were divided into four categories:

1. <u>Staff</u>: nurs*, medic*, health, healthcare, "health care",  "health-care", hospital, "allied health", "allied-health", personnel, professional*, worker*, employee*, crew*, team*, auxilliar*, aide*, assistant*, practitioner*, technician*, workforce, staff, nurs*, doctor*, clinician*, physician*, consultant*, registrar*, geriatrician*, gerontologist*, psychiatrist*, and hospitalist*.

2. <u>Patient</u>: Old*, elder*, aged, and senior

3. <u>Workplace</u>: ward*, hospital*, unit*, setting*, and institution*

4. <u>Confusion</u>: amnesi*, "memory loss", dement*, amentia*, "frontotemporal lobar degeneration", encephalopath*, leukoencephalopath*, Alzheimer*, deliri*, depressi*, "cognitive impairment", confusion, "mental health", "mental hygiene", "mental illness", "mental incompetence", "mental incompetency", "mental impairment", psychiatric, psychos*s, psychotic, "psychological disorder", neuros*s, neurotic, delusion*, geriatric, and psychogeriatric

The search terms varied according to the each database and free text terms were used where appropriate. Searches were restricted to English language papers published between January 1980 and September 2009. Both empirical and non-empirical papers were included.

**Selection**

A staged selection process was undertaken once duplicate references had been removed

1. The titles of references were reviewed

2. The abstracts of articles passing first stage were reviewed

3. The entire texts of the article passing the first two stages were reviewed

4. The Cochrane Library, the British Medical Journal and the Lancet were manually searched for relevant articles

For inclusion in the literature review, papers had to focus on or contain an element relating to each of the following:

- The acute healthcare setting

- Occupational outcomes or variables for healthcare staff

- The care of cognitively impaired older patients. The terms "confusion" and "confused" are used where findings are not specific to a specific diagnosis or impairment or where these are unspecified.

Articles known to authors not identified through the electronic search but meeting the inclusion criteria were included, and the reference lists of included studies were searched.

Of the papers that were identified through the literature research, 21 were considered key papers, with 11 of these being published in the UK, and 5 were empirical in nature. No systematic review of this area was identified.

### 2.2.3 Findings

The findings are presented under the following headings: the physical environment; organisational systems and culture with respect to patients; organisational systems and culture with respect to staff; dealing with patients and relatives; and related research literature.

**The physical environment**

In contrast to the built environment of many nursing homes, the built environment of general wards in acute hospitals is not conducive to caring for older patients with mental and behavioural disorders (27-29). Hospital wards are unfamiliar to patients and contain many environmental hazards (27, 30). Confused older patients are often distributed across a ward in such a way that makes overseeing them and catering for their basic needs a challenging task for healthcare staff (27, 30). Once admitted to a general hospital ward, the environment offers few opportunities for confused older patients to engage in activities to stimulate their bodies or minds (29). The built environment may become even more hazardous and inhospitable for confused older patients at night when light levels are low, and when the number of staff available to care for patients is typically reduced (27).

The unsuitability of the acute care environment may also have deleterious effects on the working lives of acute healthcare professionals. In a study examining the care of people with dementia in acute hospitals, Nolan (30) described the impact of the built environment on nurses' working lives. Participants believed this affected their ability to care for other patients, particularly when caring for more than one person with dementia, and resulted in feelings of guilt and frustration.

Philp and colleagues (31) found that compared to nursing home staff, hospital staff working in geriatric and psychogeriatric wards had relatively low morale. The main factors underlying this finding were excessive bureaucracy in hospitals and lack of space on wards compared to nursing homes.

**Organisational systems and culture with respect to patients**

Overall, the service provided to older patients in general hospitals has been described as poor and in need of improvement (10). One line of inquiry suggests that care of older patients is not seen as a priority by staff, with ward routine being more important than patient care (32). As a result, researchers have reported the overuse of restraint on older patients in acute settings (27) and patients being ignored by staff (28). However, such evidence reflects only a part of the complex system within which healthcare staff work. Older patients with mental and behavioural problems are often not assessed properly (27, 29) and can be transferred around the hospital, with most staff being powerless to do anything about it (28). Many healthcare professionals receive little or no training on how to care for this patient group (30) and as a result find it very difficult to communicate with the patients and understand their reality (33). Nurses find many characteristics of the patient group and their care to be stressful (34). For example, healthcare staff report a lack of time in the acute setting to provide care (27, 28, 35), which can result in significant levels of occupational stress (28, 35).

Borbasi and colleagues (27) presented the findings of a large survey of healthcare professionals regarding provision of care for patients with dementia in the acute setting. Staff lacked time to care properly for patients with dementia, particularly as they took longer to care for than other patients. Overall, the reliance on the medical model of care delivery in acute hospitals was highlighted as a fundamental problem in providing care for dementia patients, being a model that emphasises only patients' acute conditions. Additional problems of the acute care system related to the length of time taken to secure input from healthcare providers in the community, which participants suggested resulted in patients being admitted unnecessarily, often for long periods of time.

Cunningham and Archibald (36) reviewed how patients with dementia in acute hospitals have healthcare delivered in ways that are contrary to established knowledge about dementia. For example, bed moves required during hospital admission may cause distress and exacerbate confusion. The pressure to discharge patients quickly and the cessation of convalescent care in hospitals was also believed to have a negative effect on confused older patients, who often require a long period of convalescence and may be unable to return home following treatment.

Eriksson and Saveman (28) presented evidence that hospital nurses caring for confused elderly patients complained of poor cooperation between the different providers, inadequate information on patients' normal functioning, and admission of patients without medical needs onto acute hospital wards. Participants also criticised the number of beds allocated specifically for patients with dementia as being insufficient, and that the social care of confused older patients was inadequate.

At the interface of patient-staff relationships, nurses surveyed by Eriksson and Saveman (28) felt there was not enough time to get to know patients or ensure they received a good level of care. As a result, they felt their work involved guessing how to solve problems. Moreover, nurses described the frustration of having to help someone who resists or misinterprets their actions, and described feeling inadequate to the task, no matter how hard they tried.

**Organisational systems and culture with respect to staff**

It is evident that staff at all levels receive little training on how to provide care for confused older patients (27, 32, 35, 37) and find it difficult to relate any training they do receive to healthcare they provide (32). Significant differences in expertise appear to exist across different ward specialties, but overall staff in acute hospitals lack knowledge in this area (27, 29, 30, 35, 38, 39). This leads to feelings of powerlessness, frustration, failure, defeat and dissociation amongst staff (35, 40). Improving training and services may rely on an individual with a particular interest in this area (10, 37). Many other aspects of caring for confused older patients are also potentially

stressful for staff (34), including working at night when staffing levels are reduced (28), and poor links between hospitals and social services (27). Conversely, amongst ward staff, formal support and supervision were believed to have a positive effect on job satisfaction and work stress (40-43).

Pulsford and colleagues (37) surveyed UK Higher Education Institutions, to examine coverage of dementia in pre-registration and pre-qualifying courses for health and social care professionals, and continuing professional development (CPD) courses on dementia care. Coverage of dementia in adult branch nursing programmes was limited and sometimes non-existent. Occupational therapists and social workers were said to receive similar input to adult branch nurses. CPD courses were provided by around 70 percent of institutions, but there was a lack of diploma and degree level courses on dementia. One area of particular concern was the lack of formal training on management of challenging behaviour.

A survey of the inpatient nursing care provision for older people highlighted problems relating to staffing levels, skill mix, sickness and absence, and staff recruitment (44). There was a relationship between turnover and sickness in areas where there had been a change in leadership.

Atkin and colleagues (39) found that nurses perceived themselves to lack the skills needed to recognise and manage co-morbid mental illness, and believed care for confused older people was outside of the competencies of general nurses. The key area of training need for nurses was the management of problematic behaviours and violent incidents associated with dementia and delirium. Training offering formal accreditation was perceived to be a way to recognise and develop expertise.

Benjamin and Spector (34) examined stress in staff caring for patients with dementia in a general hospital ward, a psychiatric hospital ward, and a specialist unit caring for this patient group and found that staff in all facilities attributed considerable stress to there being insufficient staff on duty. Another significant stressor related to the interpersonal relationship demands of the less cognitively-impaired patients, compared to what were experienced as the more purely physical needs of severely cognitively impaired patients.

Cocco and colleagues (45) examined stress among care-giving staff in different care settings (nursing homes and acute geriatric wards), and found that staff in acute geriatric wards of general hospitals experienced significantly higher levels of stress and burnout than staff in nursing homes. Overall, nurses without professional training (auxiliary nurses) experienced higher levels of burnout, and a high patient-to-worker ratio was predictive of emotional exhaustion.

Duquette and colleagues (42) found that support from superiors and peer cohesion were important means to reduce burnout among geriatric nurses. Similar results were reported by Berg and colleagues (41), who concluded

that work-related social support was a significant factor in decreasing the impact of stress and job strain among nurses working in that environment.

Cunningham and Archibald (36) inferred that the skills and training provided to healthcare staff in acute hospitals should reflect the realities of their workload, and that nurses and healthcare professionals need more education and training to support confused older patients. In the same vein, Doherty and Collier (35) argued that a larger portion of pre- and post-registration nursing training should be devoted to dementia care.

## Dealing with patients and relatives

Confused older patients display a range of characteristics that healthcare staff can find difficult to accommodate. For example, the problems that confused older patients have with communication means that healthcare staff cannot obtain a medical history or background information directly from patients (27). This can cause ethically difficult situations for staff relating to patient capacity and consent, such as having to administer medication to patients against their will, which can result in work stress and feelings of frustration for staff (28, 35). Staff may also fear the threat of physical violence from patients, whose behaviour can be difficult to predict, or frustration at not being able to do anything to improve the patient's confusion (28). As a result, some healthcare staff may find it difficult to establish reciprocity (33) and some avoid confused older patients (27, 38).

A little-explored area in relation to the care of confused older patients in acute settings concerns their family carers. For example, Nolan (30) discussed visiting times as being difficult for staff caring for confused older patients, because of the sudden increase in the number of unknown people on the ward. In contrast, Borbasi and colleagues (27) described family members of confused older patients as assets to healthcare staff, because of their potential to facilitate their care. Clearly, the relationships between family members and staff are complex. For example interviews with staff on dementia wards revealed a mutual wariness where relatives were afraid to air their concerns for fear of reprisals against the patients and staff were afraid to communicate with relatives lest they be held responsible for perceived failures in the care provided (46). Some patients may even be prone to mistreatment from unscrupulous family members, or from relatives who could increase their dependency by insisting they adopt a sick role. In addition, stressed or grieving family members may require substantial support from staff.

## Related research literature

A large body of empirical research exists on work and organisational factors associated with the provision of care by healthcare staff to older patients with mental and behavioural disorders in residential and other non-hospital

care settings (47-63). While it may be tempting to extrapolate the findings from such research into the acute care setting, caution should be exercised in so doing (27). There are important differences in many aspects of work organisation and the physical and psychosocial work environments between acute hospital wards and other care settings. For example, prevalence rates of mental and behavioural disorders differ significantly across different care settings (34, 64). There are also differences between hospital and residential care settings in terms of the type and amount of relevant staff training on mental and behavioural disorders, staff's overall levels of caring experience, the ratio of staff to patients, the physical working environment, staff's access to relevant equipment, and so forth (29, 30, 34). Staff caregivers experience significantly higher levels of stress and burnout in general hospitals than in residential care (31, 45).

### 2.2.4 Conclusions

This section describes complex processes that link the environment, staff, patients, and their families. No single or systematic review of the literature in this area was found and no unifying working model or theoretical framework was identified. Nonetheless, overall the literature shows that staff find the provision of good quality care for older patients to be difficult, but even more so for confused older patients.

## 2.3 Literature review: experience of older people with dementia in general hospitals

### 2.3.1 Introduction

Chapter 1 argued that the care of people with cognitive impairment is not good enough. The development of recommendations for achieving better care for these people depends upon a more thorough understanding of the experience of such people , their carers and the staff looking after them – what actually happens, and why it happens. On the basis that dementia is the most commonly studied condition causing cognitive impairment in older people in general hospital, this literature review focussed on this condition.

### 2.3.2 Method

The aim of this literature review was to identify and summarise published research articles that examined the experiences of people with dementia and their families and carers of acute hospitalisation.

**Search strategy**

The following databases were searched: MEDLINE, EMBASE, CINAHL, psychLIT, ASSIA and the Cochrane Register of Controlled Trials. The Bradford dementia care group reading resource list was also searched. Key search terms used were: dementia*, caregiver*, hospital*, aged over 65 or over 80*, research*(*denotes core terms used in each search); patient satisfaction, experiences, expectations, carer, decision-making, support systems, patient participation, acute admission, in-patient, terminal, prognosis, proxy decision-making. Delirium was also used as a search term in addition to dementia. Each search was conducted using "AND" then "OR" as within and between categories. The search terms used varied according to the individual database used and the mapping key terms available. Free text terms were also used and various combinations specific to the term catalogues as listed in each database. Database searches were limited to English language papers published from 1990-2010. All research designs were included.

**Selection**

Duplicate references were identified and removed. A three stage selection process was undertaken by a post doctoral researcher for the remaining references:

1. Titles of references were reviewed

2. Abstracts of articles passing the first stage were reviewed

3. Entire text of the article passing the first two stages were reviewed

Inclusion criteria:

- Studies of the experience of older people (most participants >65) with dementia, or their carers, in a general hospital

- No restriction on research design.


Exclusion criteria:

- Studies not in dementia or in early onset dementia

- Studies not in acute care of in-patients of general hospitals

- Studies not describing the experiences of people with dementia (e.g. bioscience studies, studies of staff only, protocols, technological interventions)

- Non-research studies

- Non English language studies

- Studies unavailable

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Articles known to the authors but not identified by the search but meeting the criteria were also included, and the reference lists of included articles were searched.

**Data extraction and analysis**

The study design, nature of the data and number of participants were summarised. A narrative description of each paper was prepared describing the aim, method, main findings and conclusions.

## 2.3.3 Findings

**Search findings**

Seven articles representing 6 studies were selected for review. The results of the search and selection process are shown in Figure 1. A narrative review of the 7 articles is given below, presented by year of publication, and the design features of the papers are summarised in Table 1.

**Figure 1. PRISMA (65) diagram of the search process**

```
┌──────────────┐   ┌─────────────────────────────────────────┐
│              │   │ Citations from database search n =174   │
│ Identification│   │           Medline n=163                 │
│              │   │           CINAHL n=6                    │
│              │   │           PsychINFO n=5                 │
│              │   │           ASSISA n=0                    │
│              │   │           Cochrane n=0                  │
│              │   │           Bradford n=0                  │
│              │   │           RCN n=0                       │
└──────────────┘   └─────────────────────────────────────────┘
                                    │
                                    ▼
┌──────────────┐   ┌──────────────────────────┐   ┌────────────────────────────────────┐
│              │   │ Citations after          │   │ Excluded n=159                     │
│ Screening and│   │ duplicates removed       │──▶│ Not dementia or early onset only   │
│ eligibility  │   │ n =162                   │   │ n=19                               │
│              │   └──────────────────────────┘   │ Not acute care in general hospital │
│              │                                   │ n=72                               │
│              │                                   │ Not patient experience n=48        │
│              │   ┌──────────────────────────┐   │ Not research n-8                   │
│              │   │ Papers meeting criteria  │   │ Not in English n=4                 │
│              │   │ n=3                      │   │ Unavailable n=8                    │
│              │   └──────────────────────────┘   └────────────────────────────────────┘
└──────────────┘
                                    │
                                    ▼
┌──────────────┐                                  ┌────────────────────────────────────┐
│              │                                  │ Papers meeting criteria            │
│              │                                  │ already known to researcher        │
│              │                                  │ n =3                               │
│ Included     │   ┌──────────────────────────┐   └────────────────────────────────────┘
│              │   │ Papers included in review│◀──
│              │   │ n=7                      │   ┌────────────────────────────────────┐
│              │   └──────────────────────────┘◀──│ Papers identified from search      │
│              │                                  │ of selected articles               │
│              │                                  │ n=1                                │
└──────────────┘                                  └────────────────────────────────────┘
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**Table 1. Summary of the papers reviewed**

| Study | Method | PWD age range (years) | Setting |
|---|---|---|---|
| Tolson et.al (66) | Mixed methods: document survey, documentary audit and critical incident event technique (carer interviews) | 41, aged >65 | Two acute medical and two older people wards in two Scottish hospitals |
| Norman: PhD thesis (67) | Ethnography grounded theory, using observations, focus groups and interviews | 8, ages not given | Acute wards in one English hospital |
| Norman (68) | Ethnography grounded theory using observations | 8, ages not given | Acute wards in one English hospital |
| Formiga et.al. (69) | Structured telephone interview of carers after death of patient with dementia, compared with patients dying with heart failure | 37, mean age 87 | Acute care units in two Spanish hospitals |
| Douglas-Dunbar et.al (70) | Carer interviews | 9, aged >65 | Care setting not given, one hospital in England |
| Naylor et.al (71) | Mixed methods: case studies and baseline data collection for RCT clinical trial | 10 aged 72-89 | Acute hospital wards in three hospitals. |
| Cowdell (32) | Ethnography using social participant observation | 11, aged 80-93 | Old age wards in an acute hospital in England |

## Narrative reviews

Tolson (66) aimed to examine what constitutes best nursing practice during a period of hospitalisation for a person who has coincidental dementia, using a mixed method study of documentary survey, audit and critical incident techniques concerning 5 patients in Scotland. The paper's main conclusions regarded poor recognition and documentation of dementia and the relationship of this to the quality of care. Patients were often unsettled in hospital because they did not understand where they were, carers were distressed by communication failings that affected their loved ones, and carers were distressed by their perception that staff did not understand the condition.

Norman's PhD thesis was published in 2003 and a paper arising from it was published in 2006 (67, 68). She aimed to explore how people with dementia were cared for in general hospital wards in England by looking at 8 patients'

experiences, taking an ethnographic approach. Norman found that the way behaviour was interpreted depended to a large extent upon the staff mix and ward culture. The experiences of patients with dementia were characterised by boredom, constraint, isolation and suffering. Carers valued the work done by professionals but often felt that they could not share their own knowledge about dementia care and participate fully in decision making such as discharge planning. There were frequent discrepancies about perceived standards of care between health professionals and family carers.

Formiga (69) aimed to compare the experience of people with dementia (n=37) and heart failure (n=65) who had recently died in a Spanish hospital. Data were obtained by structured telephone questionnaires conducted with the family carer within one month of the death. No differences in the markers of care between the groups were identified, and the recommendations made were not specific for people with dementia.

Douglas-Dunbar (70) aimed to develop a support service for carers of older people with dementia admitted to a general district hospital in the UK, by the use of semi-structured interviews with a convenience sample of 9 carers of people with dementia who had recently been discharged from hospital. The main inferences drawn were the importance of staff recognising the needs of the carers as well as the patient, and the need to develop a therapeutic relationship between staff and the carer as well as with the patient.

Naylor (71) aimed to explore the need for improved care in the transition from acute hospital to home for older people with dementia and/or delirium using five detailed case-studies. These highlighted the complexities of providing seamless care following discharge and the adverse consequences when inadequate plans were made. Common factors identified which can lead to failed discharges were: poor written and verbal communication between agencies and health professionals regarding medication and health care; confidence and willingness of family to undertake or resume caring; non-recognition of dementia and/or delirium during the hospital stay; rushed discharge; and a lack of adequate support for the more complex chronic conditions requiring regular monitoring at home.

Cowdell (32) aimed to investigate the experiences of patients and nursing staff in relation to the care of older people in an acute hospital setting. An ethnographic approach was used involving observations made on 11 people with dementia in an English hospital. Patients' experiences were found to be largely negative and, although in general nursing staff wished care to be of high quality, some nevertheless adopted task–focussed and impersonal procedures. The staff who gave the most direct care often had little training in the care of people with dementia, other than dealing with violent behaviour.

### 2.3.4 Discussion

The methods used in this review were designed to seek out research papers that were specifically focussed upon patients with dementia in acute general hospital care. In doing so, many other articles where the experiences of people with dementia were part of larger studies will have been excluded. Finding such articles was difficult: only three of the seven articles reviewed here were actually found by electronic search, the others coming from the researcher's prior knowledge of the field. It is therefore likely that there are more articles not identified by this review, particularly from countries other than the UK. Despite these limitations, the findings of this review go further than merely reporting the alarm and concern about patient and carer experience raised by pressure groups and the media.

A few small-scale studies from divergent settings were found regarding the experience of people with dementia in acute hospitals, confirming that there are reasons to be concerned about the issue. The evidence portrays patients with dementia being bewildered, bored or distressed while in hospital and failure by staff to recognise the presence of dementia or to understand patients' behaviours. A common finding was the importance of family carers.  Not only were they affected by the patients' illnesses as would any relative of a sick person, but they held knowledge about the person with dementia that was relevant to their care, and they were critical in planning the patients' future because of their roles as advocates and providers of care. Thus, instead of the simple patient–professional relationship that typifies many health encounters, the experience of people with dementia in hospital is affected by a triangle of relationships including the carer.

Confirming the view expressed in Chapter 1, the review of the literature shows that the concepts of person-centred care and relationship-centred care appear to be suitable theoretical frameworks with which to interpret these findings. The first construct stresses the importance of respect for the person with dementia to optimise response to them and hence enhance their experience. The second emphasises that, although the person with dementia remains the centre of care, they experience it through their relationships with those around them, including both staff and their carers. Task focussed care is not person-centred, and care that overlooks the carer is not relationship-centred.

## 2.4 Summary of chapter

The experience of people with cognitive impairment in general hospitals, dementia in particular, is of concern as it is often distressing for them and for their relatives. It also presents challenges for the staff who care for

them. Variations in quality of care have been attributed in part to the physical environment, but also to staff training, attitudes and resources. There are likely to be complex interactions between the ability of staff to deliver high quality care, their experience of stress and "burn-out", and patients and families' experiences. These factors have not to date been drawn together systematically in the existing literature.

Staff may be prone to negative feedback or a vicious spiral, where poor care leads to staff burn out which results in worse care. The reverse argument is that positive feedback might engender a virtuous spiral, where good care leads to job satisfaction and stability, which results in even better care. The aims of the research described in subsequent chapters was to gather information that might help identify the causes of the vicious spiral of care so that it can be broken, and that it might identify the necessary conditions to facilitate a virtuous spiral.

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# 3 METHODS

## *3.1      Staff and organisational study*

### 3.1.1 Research questions

An interview study was undertaken of general hospital staff's confidence, competence and training and of the organisational and system factors that affect their ability to provide care for older people with cognitive impairment. The research questions were:

- What are general hospitals' staff's concerns and anxieties about dealing with older patients with cognitive impairment, and what confidence have they in their own competence to deal with such patients?

- What is the prevailing organisational culture (hospital and ward level) regarding older people and what are the organisational systems and management practices for older people with cognitive impairment?

- What are staff's suggestions for systems-level improvements to service delivery and for personal/professional development?

### 3.1.2 Methodology

The methodological orientation of this study was based on Consensual Qualitative Research (CQR) (72, 73). CQR is a branch of qualitative research which has developed in the field of psychology. It shares features of other qualitative approaches such as grounded theory, phenomenology and comprehensive process analysis. The five central components of CQR are:

- A semi-structured data collection technique that uses open-ended questions

- Use of multiple judges throughout the data analysis process

- Consensus to allow judgements to be made about the meaning of data

- At least one auditor to check the work of the primary team of judges

- An analysis that clusters data into categories

This process provides summaries of each category, and examines differences in responses between different groups of participants (72).

### 3.1.3 Method

**The research team and reflexivity**

Interviews were conducted either by AK or AG. AK was a male research fellow in applied psychology; AG was a female professor of occupational health psychology. Neither were NHS employees. Both interviewers were trained and experienced in qualitative research and analysis methods. AK conducted 51 interviews and AG conducted 9 interviews. There was also one outside auditor, JG, a professor of medicine of older people.

No relationship with participants was established prior to the commencement of the study. At the beginning of each interview the researchers introduced themselves to the participant. Participants were told that the purpose of the interview was not to audit practice, but to gain insight into experiences, thoughts and feelings of healthcare staff in relation to older patients with "mental health problems like dementia, delirium and depression". The terms "confusion" and "confused" were used almost universally by interviewees in response to this question and these terms are used in the results. The researchers also highlighted to each participant that they were independent researchers, not NHS employees. The opening questions of each interview asked about background information so as to ease the participant into answering more specific questions and to build the relationship between researcher and participant.

**Participant selection**

The sampling frame was 11 study wards across two hospital sites of a single NHS Trust, with no liaison psychiatry service. Interviews were sought with staff from participating wards. Participating wards for each specialty were as follows: 2 respiratory, 1 rheumatology, 2 orthopaedic, 2 healthcare of older people, and 4 other general medical wards. Seven of the wards were located on site one and the remaining four wards were located on site two. The generic structure of each hospital ward comprised 4 bays laid out in a linear fashion, with 6 patient beds in each bay. Wards also contained 4 side rooms for patients, with 1 patient bed in each side room. Wards differed in terms of their year of construction, floor space, and presence or absence of additional facilities (e.g. dayroom, dining room, etc).

A quota sampling method was employed to ensure that the sample of healthcare staff who were interviewed was an accurate reflection of a typical ward within the selected specialities. For example, nurses were the most numerous professional group working on participating wards, so

relatively more interviews were sought with them than other professional groups.

In collaboration with ward managers, purposive sampling of typical cases (staff members) was conducted within the following professional groups: healthcare assistants, staff nurses and deputy ward managers, occupational therapists, physiotherapists, junior doctors, and trainee specialist doctors. All participants were invited in person to participate in the research with the exception of consultants who were invited by email. Two individuals declined to participate in the research. Substitutes with similar characteristics were invited to participate in their place. Following each interview, participants were asked to complete a brief self-administered questionnaire and specify their age, gender and ethnic group. The ethnic group item included in this questionnaire employed the ethnic group classifications specified in the 2011 Census of England and Wales (74).

### Interview setting

Interviews were conducted with participants either in a private room on the ward on which the participant was working or in participants' private offices. No individuals other than the interviewer and participant were present during any of the interviews. All interviews took place during the period February 2010 – February 2011. Prior to each interview, the participant was given a research information sheet to read, and was asked to sign a consent form.

### Data collection

Interviews used a semi-structured guide providing broad prompts. Three sources of information informed the development of the interview guide; the literature review presented in Chapter 2; formal discussions with six senior healthcare professionals with experience conducting research in this area; and, after constructing the first version of the interview guide, pilot interviews with three people from the research population who were not participating in the study.

Interviews focused on participants' perceptions and their perceptions of colleagues in relation to the following topics:

- Amount of direct experience with confused older patients
- Additional experience with confused older patients (e.g. personal experience or work experience gained outside of acute hospitals)
- Education and training focused on confused older patients
- Aspects of caring for confused older patients found to be difficult or demanding
- Aspects of caring for confused older patients found to be interesting or rewarding

- How well doctors, nurses and allied health professionals work as a team when caring for confused older patients

- How well doctors, nurses and allied health professionals work with members of the wider healthcare team

- Confidence in competence with regards to caring for confused older patients

- Recognition and rewards from patients, relatives, colleagues and managers

- The physical work environment

- Work schedules and targets with regards to caring for confused older patients

- Staffing establishment

Participants were asked for examples to support responses where appropriate. The sampling frame proved adequate for the purposes of data saturation, as no new themes were emerging from any of the professional groups after 60 interviews.

Interviews lasted between 20 and 70 minutes. All interviews were audio-recorded with participants' consent and transcribed verbatim by professional transcribers. Transcripts were then checked by the researchers against the audio recordings for accuracy.

**Data analysis**

The qualitative data management software NVivo 8 (75) was used. AK and AG read through all of the interview transcripts to become immersed in the data. Following a series of discussions on the content of the transcripts, AK and AG developed a preliminary list of categories (the coding scheme) for use in the analysis. This coding scheme was tested on a small sample of transcripts, representative of all professional groups sampled.

Following testing on the selected transcripts, the coding scheme was presented to JG for an auditing review. The auditor's task was to examine the categories, their groupings and descriptions. The auditor offered comments and suggestions to improve the coding scheme. Following discussion, AK, AG and JG agreed upon a revised coding scheme. All previously coded interview transcripts were then recoded using the revised coding scheme. Previously uncoded interview transcripts were selected once more, and were added to the sample of transcripts on which the revised coding scheme was tested. This auditing process was repeated until no new categories were needed and until the auditor had no additional comments on the coding scheme. This stage was reached after three separate auditing sessions, whereupon 12 interviews had been coded. Additional changes to the coding scheme occurred after this point, but these related to minor

changes in wording of categories rather than alterations to the structure of the coding scheme.

The data analysis followed the principles of CQR (73) with two exceptions. First, in the original formulation of CQR every utterance made by participants should be categorised, regardless of relevance or importance (73). However, in this research participants' utterances were only coded where they contained an aspect of evaluation or expression of an opinion or feeling; the small numbers of purely descriptive utterances that were free of evaluation were not coded. Secondly, to ensure maximum analytical rigour and to minimise the possibility of data being coded subjectively, both researchers independently coded transcripts and discussed codings until consensus was reached for every coded utterance.

The initial raw data were placed into 40 separate categories. Each of these categories was then examined individually in terms of their nature, variety, degree of consensus within and between professional groups, and frequency of occurrence. A concise summary was thus produced for each of the 40 categories.

## 3.2 The observation and interview study

An observational and interview study was undertaken of patients in a general hospital who also had cognitive impairment, their carers, co-patients and the staff looking after them was undertaken. The research questions were:

- What are the effects of cognitive impairment  in older patients in general hospitals upon the care delivered and the outcomes of that care as perceived by the patients, their families, caregivers and advocates, the immediate ward staff, and co-patients (other inpatients without cognitive impairment)?

- What would improve the experience of hospitalisation from these three perspectives?

This following section discusses issues relating to conducting research with people with cognitive impairment, and how these impacted on the decision to use the principles of ethnography and grounded theory.

### 3.2.1 Research and the person with cognitive impairment

Much has been written about the ethics of conducting research on or with people who lack the capacity to consent (21, 76). Even in traditional

ethnography where observation is the primary method of collecting data there is an expectation that interaction between the observer and the observed will take place that will inform the data collection and analysis (77). It is possible to conduct a research interview with a person with dementia by using picture board and other language aids and by interpreting non-verbal as well as verbal responses (78). However, the person with dementia needs to be in the environment being discussed in order to contextualize the questioning. In this study interviews were conducted at home and not conducted in hospital, because in hospital people were either too ill or too worried about voicing criticisms while still receiving care.

Thus, to design a study that aimed to understand the experience of the cognitively impaired older patient the reality that these patients could not reliably tell their stories or reflect back on their experience in hospital meant that inevitably there would have to be interpretation beyond that normally expected in qualitative research (79). In recognizing this position, the approach of ethnography to watch, interpret and evaluate the experiences of cognitively impaired  older patients on hospital wards as chosen (80). In-depth interviews with family caregivers were also used, many in the presence and active involvement of the congnitvely impaired older patient, and some co-patients in order to gain different views of the patients experience as well as the experience of those people most affected by the hospitalization of the cognitively impaired.

The researchers attempted to view the world from the perspective of the cognitively impaired older patient and not from the perspective of their family members or the staff caring for them (81). This was a difficult position to take. However there is a precedent in the philosophical approach of person-centred care for people with dementia as introduced by Kitwood (82) and further developed by Brooker (83, 84). Brooker's (84) explanation of person-centred care uses the acronym VIPS to represent the essential components of a person-centred approach (Table 2). The third component, seeing the world from the perspective of the person with dementia, is the one most relevant to the question of interpretation but it is one that requires compassion and imagination. It is with this attitude that both data collection and analysis were approached.

### Table 2. The VIPS Framework

| V | **V**alue people with dementia and their carers |
| I | Treat people with dementia as **I**ndividuals |
| P | Use the **P**erspective of the person with dementia |
| S | Provide a positive **S**ocial environment |

### 3.2.2 Methodology

Traditional ethnography is a branch of anthropology dealing with the scientific description of culture (85). In this study, the cultural group studied was cognately impaired older people. As in the staff and organisational study and for the same reasons, the terms "confusion" and "confused" are used in this section to refer to people with cognitive impairment and associated behavioural disturbance. The observations were restricted to the life of the confused older person when admitted to hospital. The culture under study was revealed through the interactions among the confused older person, the family caregiver, the other patients who shared the ward (co-patients) and the various types of staff who cared for them.

Describing the setting and actions of the confused older person in hospital was not sufficient to meet the research aims. It was necessary to understand the interactions and processes in order to represent the experience. Through the addition of the principles of grounded theory to the analysis of the data, it was possible to study what was happening and make a conceptual rendering of the actions. Grounded theory methods provide systematic guidelines for probing beneath the surface (86) which is what was needed to understand the experience of the confused older patient and the other key players.

### 3.2.3 Methods

**Setting**

This study was integrated with the Medical Crises in Older People NIHR Programme Grant for Applied Research(87). One work-stream in the programme focused on the care of cognitively impaired older people in the general hospital. The first phase of this work was prospectively to follow for 6 months a cohort of 250 older people admitted to a general hospital who had a co-morbid mental health problem - the MCOP-BMH study (88).

**Sample and recruitment**

Participants were recruited from two sites of an 1800-bed teaching hospital providing sole general medical and trauma services for a population of 660 000. All participants were already recruited to the MCOP-BMH study (88), and had been admitted to hospital for acute medical care. Individuals aged over 70 with unplanned admission to one of 11 wards were eligible for inclusion. Wards types were similar to each other, and were chosen to be representative of those receiving unselected acute admissions. The hospital did not have a liaison psychiatry service. All participants for the present study were identified by the researchers on the MCOP-BMH study (88). Recruitment occurred over 12 months.

**Design**

This study used non-participant observation in the hospital setting and in-depth interviewing after discharge at the patients home to answer the research questions. Only one interview was undertaken with each caregiver. Observations were undertaken by three researchers: FJ, PC and BR. All three had trained as nurses and were post doctoral experienced qualitative researchers. Interviews were undertaken by two researchers: FJ and PC.

**Data collection**

Before each observational period the researchers from the MCOP-BMH study (88) and this study liaised to identify appropriate patients on the study wards, and arrangements with the study ward for the observation were made. On arrival, verbal consent was checked with the confused older patient if possible. If family members were visiting verbal consent was also obtained from them. If the patient was not communicative for whatever reason, consent to observe was checked with the ward staff. Careful monitoring of verbal and non-verbal cues to the acceptability of the researcher's presence was continuously made.

Observations were undertaken in various sites on the wards including the multi-bedded bays, patient lounge areas, near the nurses' station and while walking with patients being observed.  Most observations ended naturally when the patient was needed for a procedure or the researcher felt the observation had become intrusive.

Hand-written field notes were completed during the observations (89). Many field notes included a description of the ward in terms of noise and busyness; patients' bed areas were described and sometimes detailed descriptions of patient activities were made. No field notes identified place or person so these were immediately uploaded into NVivo 8.0 (75) for analysis.

Potential participants who had expressed a willingness to participate in this study at time of recruitment to the MCOP-BMH study (88) were contacted by telephone and invited to take part.  Where they agreed to take part, a date, time and location for the interview was negotiated.  On every occasion, the interview took place in the home of the participant. At the start of each interview permission was sought to continue with a recorded interview.

The interviews were digitally recorded and usually began by asking the family caregiver to tell the story of the admission to hospital. The interview guide was used flexibly as a prompt to explore the experiences of the person's stay in hospital.  Probes were used to elicit more detail on the experience of hospitalization and on any issues where hospitals and staff could improve the care given. Interviews lasted between 20 minutes and 2 hours (average 1 hour). Sometimes just the caregiver, or caregiver and patient were present. However, on a few occasions other family members

joined the conversation for brief periods. The interviews were varied and provided a considerable volume of material for analysis.

## Analysis

All the interview recordings were transcribed verbatim and anonymised. Transcriptions, interview notes, and observation field notes were uploaded into NVivo 8.0 (75) for management of data and tracking of analysis.

When the first two interviews had been conducted an inter-rater analysis of basic coding was conducted using the NVivo (75) consensus coding command. The coding was compared between four researchers (DP, FJ, PC and RH) by setting up basic coding for the main research areas which resulted in high levels of agreement between the researchers (68%- 98%). With such high level of agreement, independent coding was performed. Regular meetings were held to merge NVivo (75) datasets and reach consensus on new codes as they emerged and to discuss interpretation of the data. Coding was conducted by DP and PC.

Initial coding began after the first interviews and observations were entered into NVivo 8.0 (75). Data analysis was based around the principles of the constant comparison method using the two key stages to analyse the data (90). The initial phase involved division of data into segments possible to understand without further explanation. The selective phase then involved comparing each unit of data with all the others, and gathering the units that seemed similar to each other into provisional categories (86). The aim was to achieve a set of categories that were mutually exclusive and relevant to the emerging focus of the study.

Much of the coding in this initial phase was descriptive but actions and behaviours were also looked for. As part of the coding, the tacit assumptions and implicit meanings in actions and words were looked at. Gaps in the data were sought. Missing viewpoints of professional care providers emerged as a major deficiency and although this was provided by the staff and organisational study, after initial coding of the data, it was decided to spend more time observing staff. Researchers returned to the wards and conducted more observations by shadowing a nurse or observing from a vantage point.

As coding progressed it was possible to move on to identifying the processes at work in the data. Questions of the data included (86):

- What process is at issue here?
- How can we define it?
- How does this process develop?
- How do the participants act when involved in this process?
- What do the participants think about when involved in this process?
- What are the observed behaviours?

- When, why and how does the process change?
- What are the consequences of the process?

Coding became more focused with the organization of codes into categories. These categories represented coding groups of similar and related concepts. For example on a descriptive level, categories of behaviour for patients, caregivers and staff were developed. As regards patients, for example, more abstract interpretive labels for the subcategories indicating when behaviours were interpreted as positive/constructive, neutral, negative etc were devised. Under the positive/constructive subcategory, behaviours were listed which could be recognized as constructive, providing occupation or attempting to interact with others.

Ultimately a more abstract theoretical coding was developed where it was possible to conceptualise "how substantive codes may relate to each other as hypotheses to be integrated into a theory" (91). As theoretical coding continued, hypothesis generation with construction of a substantive theoretical explanation of the experience of hospitalisation for the confused older patient occurred. This ultimately led to answering this study's research questions.

**Protection of human subjects**

Before recruitment, approval from the local ethics committee was obtained. There were four principal ethical issues of concern. First, was the issue of conducting research with participants with limited or no capacity for informed consent; second, was prevention or minimisation of research burden since all participants were also recruited to the cohort study; third, was to clarify the role of the researcher during observations, and fourth was the confidentiality and security of the data.

Application for approval to conduct this study was presented to the local ethics committee with the MCOP-BMH study (88) to illustrate the extent to which patients and family caregivers would be requested to commit to research procedures.

Careful attention was paid throughout observations to ensure the patient was aware of the researchers' presence and to monitor continued permission throughout. Written information was provided for prospective interviewees and a signed consent was obtained for the interview and audio recording. Only one interviewee declined to be recorded but gave the researcher permission to take notes during the interview.

As regards clarifying the role of registered nurses as researchers during observations, guidance was sought from the UK Nursing and Midwifery Council. It was agreed that the observers should not influence care except to avoid harm and decisions were made as to where it was appropriate to intervene.

Finally, to ensure confidentiality of the information a secure system of managing the data was instituted. Recorded interviews were transcribed by experienced transcribers who had signed written confidentiality agreements. All participants were assigned a pseudonym and a code number, and the wards and places similarly allocated pseudonyms. Once anonymised, working copies of the transcriptions were stored on a shared access university database which was password protected.  The original discs were stored in accordance with local university protocol. Quotes cited in this report use these anonymised pseudonyms only.

## 3.3 Chapter summary

The research protocols for both the staff and organisational study and the patient observation and interview study have been detailed in this chapter. The results for each study will be presented in chapters 4 and 5 respectively.

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# 4 RESULTS OF STAFF AND ORGANISATIONAL STUDY

## 4.1 Participants

Sixty healthcare staff interviews were conducted, with an equal number of interviewees (n=12) from each of the five specialties. A total of 10 healthcare assistants, 15 staff nurses and 5 participants in each of the following professional groups were interviewed:  deputy ward managers, ward managers; occupational therapists; physiotherapists; junior doctors; trainee specialist doctors and consultants. Forty-eight of the 60 (80%) participants were female with a mean age of 35.9 years (range 19-63). Two thirds were white British.

## 4.2 Coding structure and frequency of utterances

The coding scheme used to analyse data in the staff and organisational study revealed four super ordinate themes that in turn comprised a number of different categories, outlined below.

1. Staff perceptions of patient group characteristics

    a. Aggression and violence

    b. Inability to cater for own basic needs

    c. Inappropriate behaviours, unpredictability and non-compliance

    d. Wandering

    e. Restlessness and night time behaviour

    f. Communication

    g. Protecting patient dignity and ethical issues

    h. Requirement for disproportionate amount of staff time

    i. Institutionalisation

2. Staff perceptions of the challenges and impact on them of working with confused older patients

    a. Initial assessment, medical clerking

    b. Management of patients

    c. Patients' relatives

d. Co-patients and their relatives

e. The general public

f. Experience gained outside general hospital settings or formal training

g. Education and training

h. Job expectations and career aspirations

i. Confidence in competence

j. Staff responses to patients and their care

k. Job satisfaction and rewards

l. Psychological well-being at work

3. The ward environment

a. Ward characteristics

b. Ward layout

c. Provision of activities on the ward

d. Ward facilities and equipment

4. Organisational factors affecting staff

a. Unsuitability of the acute care setting for patients' needs

b. Hospital as a hazardous environment

c. Avoiding admissions

d. Staffing establishment

e. Out-of-hours provision

f. Teamwork between doctors, nurses and allied health professionals

g. Wider healthcare team

h. Specialist support within the hospital

i. Professionals outside the hospital

j. Schedules and targets

k. Patient documentation

l. Hospital, Trust and NHS management issues

Table 3 shows the frequency of utterances according to the coding system. These results provide a summary of those themes that were most commonly mentioned by the sample as a whole (references) , and those themes that were mentioned by higher numbers of individual participants

(sources). These results alone do not permit any particular directional conclusions, as all utterances relating to a particular category were coded together, whether they were positive, negative, or neutral. Nor do they provide any information on how well-informed an individual was in relation to a particular subject, or how influential that individual's opinions were in influencing patient care or the working lives of staff on one or more hospital wards.

**Table 3. Number of coded utterances in each coding scheme category**

| Category | References | Sources |
|---|---|---|
| Education & training | 374 | 58 |
| Teamwork between doctors, nurses & AHPs | 302 | 56 |
| Staffing establishment | 237 | 56 |
| Patients' relatives | 180 | 59 |
| Unsuitability of the acute setting | 133 | 39 |
| Specialist support | 127 | 41 |
| Ward facilities & equipment | 120 | 49 |
| Professionals outside the hospital | 117 | 40 |
| Job satisfaction & rewards | 109 | 54 |
| Aggression | 98 | 50 |
| Schedules & targets | 87 | 33 |
| Emotional responses | 81 | 33 |
| Co-patients & their relatives | 80 | 34 |
| Behavioural responses | 73 | 40 |
| Provision of activities | 71 | 29 |
| Management of the patient | 69 | 27 |
| Communication | 68 | 34 |
| Ward layout | 68 | 39 |
| Hospital, Trust & NHS management | 67 | 21 |
| Requiring a disproportionate amount of staff time | 66 | 35 |
| Job expectations & career aspirations | 64 | 33 |
| Patient dignity and ethical issues | 63 | 26 |
| Experience gained outside | 63 | 31 |
| Ward characteristics | 63 | 27 |
| Out of hours provision | 60 | 31 |
| Confidence in competence | 59 | 34 |
| Cognitive responses | 58 | 36 |
| Initial assessment | 54 | 19 |
| Wider healthcare team | 48 | 30 |
| Inappropriate behaviours | 44 | 28 |

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| | | |
|---|---|---|
| Psychological well-being | 44 | 26 |
| Patient documentation | 30 | 16 |
| Wandering | 27 | 20 |
| Inability to cater for own basic needs | 26 | 18 |
| Hospital as hazardous | 25 | 20 |
| Restlessness & night-time behaviour | 21 | 14 |
| Avoiding admissions | 17 | 8 |
| The general public | 16 | 7 |
| Institutionalisation | 8 | 5 |
| Formal staff support services | 4 | 3 |

Note: References = number of individual utterances coded into the category across all transcripts.

Sources = number of transcripts where one or more utterance was coded into the category.

## 4.3 Staff perceptions of patient group characteristics

### 4.3.1 Patient behaviours perceived as challenging

**Aggression and violence**

Aggression and violence from confused older patients was raised as an issue for healthcare staff by most participants. Participants citing this factor as an issue belonged to all professional groups. There was a high degree of consistency in terms of description, but responses were mixed regarding staff reactions to it.

Participants viewed aggression and violence from patients as part of the job and that nothing could be done to change it. Staff tolerated aggression and violence from patients towards them, and commented that they attributed these behaviours to the patient's mental health problems rather than being a wilful and malicious act against them as an individual. The unpredictability of aggressive and violent acts was viewed as a particular problem by most participants. Aggressive and violent patients were considered difficult to manage, and references were made to involving security staff and police when patients could not be managed by healthcare staff. While all professional groups mentioned aggression and violence, there was a view that it was probably a more significant issue for nursing staff than for doctors or allied health professionals. Overall, most participants viewed acts of aggression or violence as being infrequent and as having few or no long-term consequences. However, the consequences of aggression and violence were much worse for a small number of participants. These individuals described aggression and violence as being scary, frightening, intimidating

and upsetting. As a result they felt anxious, powerless to do anything about the situation, suffered reduced confidence, and became reluctant to care for aggressive or violent patients. One extreme case of violence had long-lasting effects on a member of staff leading to counselling and time off work.

Many attributed patients' aggressive acts to uncertainty and fear. They referred to the likely importance of communication skills in helping to reduce the incidence of aggressive and violent acts, by facilitating a better understanding of what patients wanted. This was related to the issue of training and education and many staff felt that knowledge about basic conditions, communication skills, and techniques for avoiding and handling aggression and violence were important, and lacking. Staff also felt they needed more time to explain to patients what was happening, particularly during activities of daily living and during medical procedures, and to reassure them they were in safe hands.

**Inability to cater for own basic needs**

Confused older patients' dependency on healthcare staff for activities of daily living was cited by over a quarter of participants as a major issue affecting their working lives. Participants citing this factor as important mainly belonged to the nursing profession, with just a couple of references made by doctors and a physiotherapist.

Confused older patients were invariably described by participants as needing much assistance in relation to eating and drinking, washing, dressing, toileting, mobilising, and preventing injury to themselves. The tone of participants' responses was usually understanding and pragmatic but noting that these activities were time-consuming, interfered with their other work tasks, particularly caring for other patients on the ward, and were, as a result, rushed. On just a couple of occasions, participants displayed frustration in this respect.

**Inappropriate behaviours, unpredictability and noncompliance**

Various characteristic behaviours of confused older patients were cited as being difficult for staff to manage, and almost half of all participants sampled talked about these behaviours. The majority of these responses were provided by physiotherapists and members of the nursing professional group, with a few responses from doctors. Staff reported many instances of confused older patients' behaviour that they found difficult to manage. This included their general unpredictability and "mood swings", and a group of behaviours that could be described as 'non-compliant'. These latter behaviours occurred particularly during activities of daily living such as eating, drinking, taking medication, and washing. These activities were described as being demanding of staff time, as were repetitive behaviours such as persistently asking the same question, pressing call buzzers and getting out of bed. These latter behaviours were viewed as being

particularly challenging for nurses undertaking drug rounds. Some behaviours were seen as a challenge for patients' dignity. Frequent mention was made of patients removing their clothing, and causing embarrassment for co-patients. Other behaviours compromised patients' safety, such as wandering, falling, getting lost and interfering with ward equipment.

*".. doing things like trying to root in the clinical waste bins … I had to stop her from picking up sharps."*

<div align="right">Interview 55, Junior Doctor</div>

Some inappropriate behaviours were reported as affecting the safety and wellbeing of co-patients on the ward. A major challenge for staff was dealing with confused older patients interfering with co-patients and their care, shouting and screaming at night and waking co-patients.

Participants described the impact of these behaviours on them as wearing and tiring. One concluded:

*"It's distressing … you feel that you're not really doing anything other than trying to calm them down, trying to cover them up ... then they start the whole thing all over again."*

<div align="right">Interview 10, Staff Nurse</div>

## Wandering

Wandering was a characteristic behaviour of confused older patients that many staff found problematic, and this behaviour was cited by one third of all research participants as being a major issue for staff. Most professional groups mentioned wandering, but the majority of concern was expressed by healthcare assistants, nurses and junior doctors.

Participants described how confused older patients often wander around the ward, into areas where they should not be (e.g. sluice rooms, gender segregated accommodation) at the same time increasing their likelihood of falling, and raising concerns for their safety. The introduction of locked and swipe card entry doors was reported to have helped considerably, but did not entirely prevent patients wandering off the ward. On occasions, porters and security have been recruited to help find patients and encourage them back onto the ward.

*"A patient can look very plausible and just slip out when a well-meaning relative's holding the door open for a group of people... we've had a few make it to the lifts."*

<div align="right">Interview 52, Occupational Therapist</div>

The tone of responses was predominantly pragmatic and understanding. Participants viewed patients' wandering as involuntary, but felt they had limited powers to manage the situation given the physical design and layout

of the ward and staffing levels which precluded the use of strategies such as distraction. Where patients wandered, shouted and upset staff and other patients, there was pressure on doctors for sedation. Wandering was described as being more problematic at night, more disruptive to co-patients and more difficult for staff to manage owing to diminished staffing levels.

**Restlessness and night-time behaviour**

The restlessness and characteristic night-time behaviours of confused older patients were mentioned by just under one quarter of research participants as being a particular challenge for healthcare staff on acute hospital wards. Participants who cited this factor as important included nurses and doctors at all levels.

Participants commented on how confused older patients were particularly restless, hyperactive, aggressive, confused, agitated and noisy at night-time. Several noted that older patients who did not appear to be at all confused during the day could suddenly become confused at night, and that such changes were difficult to anticipate. These behaviours were perceived to be even more challenging for staff than the same behaviours during the day as there are fewer staff to manage the problem and because the disruption caused to sleeping co-patients. A junior doctor and a specialist trainee doctor commented that at night they receive more requests for patents to be sedated. The junior doctor also felt there was inadequate access to senior support at night.

*"It does actually feel very stressful sometimes at night, and that's I think when you feel the pressure to sedate patients unnecessarily and you feel the job is much more difficult... there's less senior support overnight because you can't ring the registrar who's dealing with acutely unwell people because that's what they're there to do. They're not there to talk about the smaller problems."*

Interview 55, Junior Doctor

## 4.3.2 Challenges of the care-giving relationship

**Communication**

Communication difficulties with confused older patients were mentioned by the majority of research participants as being a particular challenge for them. There was a high degree of consensus among and between participants from all professional groups. Almost all the doctors described the challenges that communication difficulties caused in their day-to-day treatment of confused older patients, and the fact that they had to adopt different strategies.

*"Sometimes you're more veterinary in your approach. And then you perhaps may not be treating them in the same way as someone else that you can talk to..."*

Interview 37, Consultant

A junior doctor described the experience of being hit by a patient and attributed it to the fact that it was not possible to communicate to that patient what was involved in taking blood samples. Occupational therapists and physiotherapists in particular found they needed to involve the wider healthcare team in rehabilitation.

*"If somebody is confused and can't easily communicate, or forgets things really quickly, of course it's really difficult to rehabilitate them to get them to do things better and in a different way…"*

Interview 23, Physiotherapist

Nurses and healthcare assistants described patients getting agitated when they did not understand what was happening to them, particularly during the procedures involved in personal care. But despite such mutual frustrations, staff felt they had to get on with the task in hand.

What was proposed as being particularly helpful, given the levels of difficulty with communication, would be more communication tools, and information about patients from the day patients are first admitted.

*"It's knowing their likes and dislikes and what their routines are and what they're capable of doing for themselves so you can, from day one, hopefully get them into that routine again. If they've got a particular night time routine... if they're used to going to bed at seven o'clock, then we'd set them down for seven."*

Interview 34, Deputy Ward Manager

**Protecting patient dignity and ethical issues**

Issues concerning the dignity of confused older patients, and ethical concerns, were mentioned by the majority of research participants as being a matter of concern for them. Staff raised several concerns relating to the care of confused older patients about personal care. Challenges gaining their co-operation with daily activities such as eating, drinking, washing, toileting and taking medication were frequently mentioned, as were the dilemmas they faced deciding how far they could go in terms of 'persuading' patients to comply.

*"The relatives come in and say 'You're not feeding them'. We are but if they don't open their mouth, you can't literally force feed them"*

Interview 13, Healthcare Assistant

Staff were concerned about the quality of patients' lives and about patients' end of life care preferences- patients who are in discomfort and want to die,

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and also those who despite their pain, do not wish to die. Making decisions for patients, who were deemed not to have the capacity to do so for themselves was felt to be a challenge.

*"I think some of it is very thorny and difficult and you feel like you're playing God sometimes, and that's not a comfortable feeling at all."*

Interview 40, Consultant

Privacy and dignity were two issues that concerned staff, particularly nursing staff and healthcare assistants. There were concerns about patients who frequently undressed, and who walked around the ward partially clothed or naked, and the unsuitability of hospital gowns in this respect. One doctor suggested that there was a need to:

*"...have nicer hospital clothes....Awful clothes, I mean, they're open at the back which is so demeaning."*

Interview 36, Trainee Specialist Doctor

Several participants raised contrasting ethical concerns related to patients' families. They felt sympathy for relatives who were having a very difficult time caring for patients at home and, on other occasions, were concerned where relatives did not appear to be the patient's best advocate.

On a handful of occasions more general concerns were expressed about the behaviour of staff, and the general quality of care provided for this patient group. Some felt strongly about this issue.

## Requiring a disproportionate amount of staff time

Over half of the study's participants referred to the 'disproportionate' amount of time confused older patients need on the ward in comparison with other patients. There was a high degree of consensus among participants, representing staff from all groups and at all levels. Consultants in particular commented that nursing staff were under particular pressure caring for these 'high maintenance' patients, and that nurses needed more support. The overwhelming consensus was that confused older patients on acute wards take up a considerable amount of staff time, and that this could interfere with needs of other patients. A few staff described some of these patients as needing one-to-one care. Nursing staff in particular described the experience of role conflict: they felt one group of patients was neglected at the expense of the other.

*"You could probably spend all day just looking after your dementia patients and just forgetting all about anyone else that's come in...because they can take up so much time."*

Interview 12, Staff Nurse

55

Doctors talked about the typical complexity of confused older patients' needs and the additional necessity of communicating with patients' families, as contributing to the determining the length of time required to care for them.

*"If you're very busy and you're trying to get things done, it's very easy, isn't it, to just...not spend the time that's often necessary to make that connection or find out from the family. "*

Interview 40, Consultant

Staff spoke about the undesirable knock-on effects of 'rushing' the care of confused patients. They described the importance of time for overcoming communication difficulties, making them comfortable, establishing rapport and trust, gaining co-operation with activities of daily living, decreasing distress and agitation, and reducing the likelihood of aggressive episodes. Several nursing staff described the frustrations for them in feeling that they were not doing an adequate job for all their patients.

**Institutionalisation**

Five members of staff referred to a tendency for patients to appear to be 'reluctant' or increasingly unable to leave the ward once they had been there for some time. Four used the term 'institutionalised' to describe what they meant. The general thrust of these opinions was that patients became used to being cared for, and became depressed due to lack of mental and physical stimulation. The overall perceived result was that once on the ward, they became unnecessarily weaker, both physically and psychologically.

*"You're trying to get them out of hospital sooner because the more they're on the bed, the more they're in the chair...they just lose their independence. And they walk when the physio is there but other than that, they don't walk and I think, you become institutionalised, that's the only word I can use."*

Interview 36, Trainee Specialist Doctor

This factor was often related to discussions about general hospital systems not being designed for confused older patients

*"If they end up sitting on a very busy ward for the next 20 to 30 days doesn't really help, and they do get institutionalised quite noticeably…"*

Interview 56, Junior Doctor

Similarly, the frequent lack of a dayroom on the ward was often related by staff to patients becoming increasingly unable to cope with going home.

> *"[A dayroom] stops them becoming depressed, it stops them becoming so withdrawn into themselves, that they don't want to leave the hospital, then when they do leave they don't know what to do..."*

<div align="right">Interview 21, Healthcare Assistant</div>

A more general attribution was made by one member of staff that some patients liked being cared for by nursing staff, enjoyed being with others on the ward, and that they became settled in hospital.

> *"You can tell … they're enjoying their time in hospital … they like being on the ward because it's their time for social interaction."*

<div align="right">Interview 53, Trainee Specialist Doctor</div>

## *4.4 Staff perceptions of the challenges of working with confused patients*

### 4.4.1 Patient assessment and management

**Initial assessment, medical clerking**

Initial assessment was mentioned by a third of the participants, representing all professional groups, but the majority of responses were provided by doctors. The vast majority of them cited this factor as a significant challenge for them. The overwhelming consensus was that medical staff found the initial assessment of confused older patients very challenging.

> *"It's often very difficult as a physician to work out what's wrong with them because they can't tell you…. [It's] like being a vet, in that you have to start right from very basics. It's very different from somebody telling you they've got chest pain or they've got ear ache or whatever..."*

<div align="right">Interview 40, Consultant</div>

Reference was made by several staff to the paucity and occasional inaccuracy of information available when patients arrived on the ward. Doctors may be told that a patient is confused, but there is often no information about why they are confused. Doctors felt it was very important that problems like dementia were made known to them quickly. Furthermore, it was pointed out that until a patient has an accurate diagnosis it is very hard to access specialist services. But even then, such services were not always easy to recruit and an opinion was expressed that this patient group was seen as a non-urgent patient group who often waited a long time for investigations.

Staff recognised that simply being in a strange hospital environment could cause upset and confusion for vulnerable patients. The challenge of not knowing what was 'normal' for a patient made diagnosis, as well as treatment and rehabilitation, harder.

*"The only thing we want to know is, is this normal for them? What can they do before they've had the fall or whatever the event was, and what are we expecting to get them back to? … That does influence our treatment."*

Interview 58, Consultant

One doctor pointed out that at medical school students are taught what they should do for one particular condition, and what they should do for another, rather than how to deal with patients with complex co-morbidities. Doctors at all levels, referred to the potential usefulness of a set of protocols, variously labelled as pro forma, systems, guidelines, care plans, objective criteria or algorithms, to assist with their initial assessment of confused older patients.

*"I think...if we had some guideline of what we needed to do to investigate, to make sure we get the right diagnosis, it would be helpful...I've got a list in my head but perhaps it's not the best list."*

Interview 37, Consultant

**Management of patients**

Challenges experienced in the daily management of confused older patients were mentioned by nearly half of the study's participants: by all but one of the doctors, half the nursing staff but few of the other groups. There were differences of opinion within and between staff groups. By far the largest group of comments in this category referred to the issue of sedating confused older patients. Doctors often expressed the view that their nursing colleagues did not agree with their decisions about sedation.

*"...the patient who has dementia … they're in a new environment, and they're more confused. And nursing staff expect doctors to calm them down...Just because somebody is just up and about, not wanting to sleep at night, and that could be how they normally are, we shouldn't artificially drug them … sedate them."*

Interview 36, Trainee Specialist Doctor

Junior doctors described the pressure they felt from nursing staff to sedate, acknowledging that this is a result of the serious disruption such patients can cause. Both juniors and their more senior colleagues acknowledged that staff shortages were at the root of much of this pressure.

*"I don't like, or in fact I don't do any more, sedation of patients for the benefit of staff...But you get the pressure from the staff to help them do*

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*their job, whereas what's actually needed is more staff to look after these people."*

<div align="right">Interview 55, Junior Doctor</div>

But pressure to sedate these patients came from other sources, not just nursing staff.

*"The pressure can come from the other patients…. One of the patient feedback groups said why didn't we sedate all these disturbed elderly patients, to which we robustly said no."*

<div align="right">Interview 59, Consultant</div>

Issues around the movement of patients within the ward and between wards were raised. Nursing staff tried to position confused older patients where they could see and hear them, and thus manage them, more easily. It was mentioned that on the same ward there were usually other (not confused) patients who were acutely ill, and who also needed frequent attention. Tension between managing both types of patient caused nurses some worry. Bed shortages elsewhere, or pressure (perceived as resulting from '4 hour wait' targets) to move patients out of the emergency department, occasionally meant patients had to 'sleep out'. When such patients were confused and elderly, it was very hard to explain to them what was happening, and this disruption was thought to cause them considerable additional distress. Staff also expressed frustration that their inability to manage such patients' problems adequately before discharge resulted in patients' readmission.

### 4.4.2 Other service users

#### Patients' relatives

Reference to relatives of confused older patients was a major point of discussion for all but one of the 60 interviewees in this study. There was some variation in their views. The nursing staff and healthcare assistants were divided as to whether patients' relatives appreciated their efforts to care for this patient group. They felt some relatives were as demanding as patients, complaining about standards of care, whereas others were grateful and appreciated staff's efforts. The amount of care and time they put in was not necessarily a reliable predictor of relatives' satisfaction.

Nonetheless, the families' views were respected as valid. It was acknowledged that there could be adverse clinical outcomes resulting from of failure to liaise with families. For example, without the knowledge that a patient would not drink tea without sugar, that patient might refuse to drink, and risk dehydration. A physiotherapist commented on the critical role that relatives play in rehabilitating confused patients.

*"I think one of the main things our service needs to do is to involve the family and the carers much more into the daily routine of the patient... They're the ones who can get the patients to do much more and who get the patients to respond to, engage with us much better."*

<div align="right">Interview 23, Physiotherapist</div>

Doctors reported their interactions with relatives more positively, appreciating their involvement in initial assessment and taking case histories. One possible reason for nurses feeling the butt of relatives' dissatisfaction more than doctors could be that they have more exposure to relatives. Another may be that relatives may often not feel empowered to deal directly with doctors, let alone complain to them, whereas they might feel more comfortable expressing their concerns to nursing staff.

Some staff expressed concerns that relatives did not always advocate, whether consciously or not, patients' best interests.

*"We always have to be aware that... a relative or a carer might have a different agenda to the patient, so we always have...to juggle that.  And to even establish, really, if some relatives have the patient's best interests at heart."*

<div align="right">Interview 38, Occupational Therapist</div>

**Co-patients and their relatives**

Issues relating to co-patients and their relatives featured frequently in the interviews, with just over half of respondents citing this category as a significant work and organisational issue for staff. Nearly all the responses characterised co-patients' and their relatives' reactions towards confused older patients as negative, using adjectives such as frustrated, angry, aggressive, upset, disgusted, distressed, frightened and intimidated.  They perceived these reactions to result from confused older patients interfering with co-patients' belongings, invading their personal space and disrupting their sleep.

*"...two or three weeks ago, the rest of the ward threatened to march out, have a mass.. self-discharge because of a patient with mental health issues who was manic, would get into bed with other patients in the middle of the night, throw water over them...she thought she was the head matron and so would boss people around and barge in on you….."*

<div align="right">Interview 50, Junior Doctor</div>

Staff reported many complaints from co-patients and their relatives, frequent requests to be moved away from a confused older patient, or for such a patient to be moved away from them. Nurses in particular often found themselves having to act as diplomats or peacemakers and viewed

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this variously, as an additional responsibility, another work pressure and, for some, a significant source of stress.

One specialist trainee doctor commented that co-patients and their relatives are sometimes helpful, pointing out to staff when a confused older patient is in need of attention. However, responses like this were very much in the minority, with only two neutral or positive utterances out of the total of eighty relating to co-patients and their relatives.

**The general public**

Seven of the research participants referred to the expectations and perceptions of a diffuse group of service users labelled here as 'the general public'. Most responses in this category were provided by healthcare assistants and nursing staff, but views about the perceptions held by the general public were also provided by a physiotherapist and consultant. Staff described having to deal with the general public's surprise and anger to find confused patients on the ward.

Participants were concerned about service users' unrealistic expectations of the quality of care hospitals could provide, and their lack of knowledge about which tasks each of the various professional groups were responsible for. They were surprised, for example, to find visitors expected someone to approach them instantly on their arrival in the ward to update them on their relatives' condition. Staff suggested more information for the general public or awareness raising campaigns would be helpful.

Much of the origin of service users' 'naïve' expectations was attributed to the media. For example, that they expected, wrongly, that a hospital would be a wonderful place.

> *"...they've seen these stupid television programmes …Their opinions are created by the likes of Holby City."*

> Interview 3, Staff Nurse

But participants were also concerned about the effect of the media's criticisms of them as a professional group, and that as a result, nursing in particular did not hold the respect it once had.

> *"You're bombarded, aren't you, in the world that we live in of about how awful the NHS is... Whenever a new story comes on, be it malnutrition or infection control, it seems to be the nurses [who] are persecuted."*

> Interview 14, Ward Manager

However, staff expressed an understanding of service users' disappointments, and awareness that the quality of provision had declined in comparison with previous years, tinged with both frustration and regret.

## 4.5 *Staff training and preparedness for work*

### 4.5.1 Experience gained outside hospital settings or training

The majority of comments about experience gained outside the hospital with this patient group were made by healthcare assistants, physiotherapists and occupational therapists. Staff who had personal experience of caring for confused older people, whether in their own family, or by previously working in a care home, invariably expressed more confidence in their ability to work with this patient group in hospital. It was suggested that it can take some 6 months to become comfortable with basic care, whereas staff who have come from nursing homes move straight into that role with no difficulty. It was also felt that such previous experience made staff better at avoiding and dealing with aggression. Understanding of the more subtle aspects of communication and behaviour were also attributed to such experience.

Participants made more positive comments about the helpfulness of experience outside hospital settings in preparing them to work with confused older patients, than they did about their formal education and training in that respect.

### 4.5.2 Education and training

The lack of appropriate education and training about the care of confused older patients was the largest work and organisational issue reported by the study's participants. All but two of the participants discussed this issue. There was a high degree of consensus about the need for training, but some variation as to the particular knowledge and skills that would be most helpful, and about when training should take place. All professional groups reported the level of relevant education, induction training and in-service training to be inadequate.  Due to the large number and variety of responses, and to analyse inter-group differences in responses, utterances in this category were analysed and are presented separately for each professional group.

**Healthcare Assistants**

Healthcare Assistants reported a complete absence of training or even induction into the care of confused older patients.  They commented on how knowledge about the condition would help staff understand patients better and be more compassionate.

Many had experience outside the profession, either from care homes or with their own relatives, and described this as useful. They noted their reliance

on the ward manager for training and expressed a strong wish for more training opportunities related to knowledge about the basic conditions and practical skills as to how to handle patients.

*"I would have loved to have been told, not told, but shown how to react and interact with these patients. I've been here for nearly two years and I've not been shown anything like that."*

<div align="right">Interview 21, Healthcare Assistant</div>

### Nurses and Deputy Ward Managers

Nurses and Deputy Ward Managers reported having some but nowhere near enough training. They felt their initial education was not adequate to prepare them for the real job and they began work feeling underprepared and under confident, a situation that was only improved by experience.

This group felt that better training about these patients should be mandatory. Some felt it was so important that they had done relevant training in their own time. They wanted knowledge (about understanding of the basic conditions, the role of medication and the availability of specialist support elsewhere in the hospital), and skills (communication skills and handling aggression). Deputy ward managers also commented that there were problems releasing staff from the ward for training.

*"It should be mandatory that you have some form of training if you're going to be given these patients, not just what the illness is about, but ways of actually being able to nurse properly."*

<div align="right">Interview 16, Staff Nurse</div>

### Ward Managers

Ward Managers commented on their own lack of training, the lack of training for new recruits to the profession, and a major disconnect between what they did learn as students and what they need to do in practice. They wanted to understand the basic conditions better and develop better skills for handling patients and aggression. In terms of training style, they regarded role-play as inadequate to teach skills. They described uncertainty about availability of relevant training within the hospital procedures, lack of money for doing so, and difficulties releasing staff from the ward. They regarded attempts to encourage nurses to 'cascade' what they learned on training courses to be impractical.

*"It's no good giving people the tools and then saying, 'Right, well, just go and do it'... good training is invaluable but … because of availability of nurses, it's given to one or two nurses on the ward...saying 'Feed back'...They can't get an entire day's worth of study from a nurse quickly telling them a few bits and bobs."*

<div align="right">Interview 42, Ward Manager</div>

**Physiotherapists and Occupational Therapists**

There were varied views from physiotherapists. Some reported little or no initial training and felt unprepared for the job in hand, and under-confident as a result. Occupational therapists reported variations in the quality of their initial education, but all agreed it should be improved. Most felt proper on-the-job training should be mandatory and exposure to senior experience colleagues would be helpful. The arbitrary nature of experience once at work was mentioned as a problem.

*"I don't think we have enough...practical kind of element to the training. … I don't think I actually saw any old people..."*

Interview 39, Occupational Therapist

**Doctors**

Junior doctors remarked on the inadequacy of medical education. Most commented that it was nowhere near sufficient given the size of the patient group. They too felt that role play was an ineffective preparation for dealing with these patients. They felt they had a basic understanding of the conditions, but not the practical skills to deal with patients, particularly those with co-morbidities. They experienced a lack of supervision with these patients, and commented that even senior doctors were not confident.

*"....considering how big a proportion people with dementia and people of an older age are actually in the hospital, I think we need more than three weeks in the undergraduate course to actually be able to deal with it… It was my least rewarding and … the training that had the least impact on me in med school, which is a big shame considering how much of my daily working life people with dementia and people that are older actually takes up."*

Interview 56, Junior Doctor

Trainee specialist doctors unanimously agreed about the inadequacy of medical school education; the size of the patient group surprised them and older people were 'not on the radar'. They too felt that training should be mandatory, particularly on assessment and treatment. They wanted practical on-the-job experience with senior colleagues. One suggested that a geriatric placement was essential for every trainee.

Consultants also commented on their own lack of training, agreed there was a need for more and better on-the-job training, and noted their own lack of confidence and competence to train juniors.

*"I just don't think … I've ever, ever, ever in my entire training, had any teaching about how to look after people with dementia."*

Interview 40, Consultant

Consultants commented that the curriculum for training was out of date in terms of the core competencies required of most doctors, and that mental

health in particular was neglected. A view was expressed that every doctor should do a rotation in Health Care of Older People.

> *"I don't know how much people have sat down and said, 'Well, what are we training people to be and therefore what are the core competencies that our doctors need?"*

<div align="right">Interview 58, Consultant</div>

In summary, staff regarded both their initial education and in-service training as very inadequate preparation to care for confused older patients, and given the size of the patient group, felt that such training should be mandatory for all staff.

### 4.5.3 Job expectations and career aspirations

Over half the participants referred to whether or not they had realistic expectations of the extent of their future exposure to confused older patients on entry to work. The majority view was that staff were surprised and even shocked, on entering their profession, to see such a large proportion of confused older people among their patients. A physiotherapist commented that students tended to think physiotherapy involved only sports therapy and elite athletes until they started going on placements.

There was a feeling that many staff did not want to work with older people.

> *"A lot of the juniors who do rotate on to here try to avoid this rotation because they … don't like old people, they don't like dementia and … they find it quite boring in a way..."*

<div align="right">Interview 56, Physiotherapist</div>

Comments were made that some nursing entrants were reluctant to provide personal care ('too posh to wash') and that there were difficulties recruiting staff to health care for the elderly in all fields.  Staff described a 'stigma' attached to this work. Nonetheless, despite not wanting to make a career in the area, some had discovered that healthcare for the elderly was a good training ground.

> *"I think healthcare of the elderly is still where you get a lot of general medicine, and for that purpose, as a trainee, it's very good."*

<div align="right">Interview 46, Trainee Specialist Doctor</div>

### 4.5.4 Confidence in competence

Staff's views about their confidence in their own competence to deal with confused older patients were mentioned by just over half of participants. Their views varied. Staff described whether or not they felt competent to deal with confused older patients, and their relatives, on the acute ward. This was often, but not always, related to their views about the inadequacy of education and training. It was also, related to experience.

> *"All the training you can get wouldn't make you confident around patients. I think the only way you really feel confident around patients is by actually getting the experience."*

Interview 23, Physiotherapist

Staff generally felt that they were confident about their medical needs, but not about their mental health needs, although a doctor who worked on a ward with many older patients suggested that staff there would feel more confident in this respect. A specialty doctor and junior doctor both described their early interactions as 'a baptism of fire'. 'Signposting' patients, knowing the role of others in the wider team, knowing 'who to ring', was also described as helping with confidence. This knowledge about, and availability, of wider resources was felt to be important.

## 4.6 Psychological impacts on staff

The first three categories in this generic theme refer to staff responses and attitudes to confused older patients: cognitive, behavioural and emotional. The final two categories concern job satisfaction and work-related well-being.

### 4.6.1 Cognitive responses to patients and their care

Comments which related to the role of knowledge and understanding of confused older patients in their care, were made by all professional groups, and by just over half of the participants. The first point made by many, largely healthcare assistants and nursing groups was that a basic understanding and experience of the nature of the condition helped them attribute patients' actions to that condition, rather than to disposition, personality or a personal issue with that member of staff. It helped staff distinguish between what they felt were 'involuntary' and 'voluntary' behaviours, and to anticipate patients' actions.

*"It's just helps to understand that … when they're shouting out, it's not that they're doing it to annoy you …"*

<div align="right">Interview 34, Deputy Ward Manager</div>

The second characteristic of cognitive responses referred to the comparison of confused older patients to children, or to people with learning difficulties. Staff reported that they believed this helped them understand things from the patient's perspective. An example was given as to why unfamiliar faces, particularly those that are not smiling and engaging, and a strange environment might be experienced as frightening by confused patients, just as they would be for a child.

Doctors found that recognising that challenging behaviour was involuntary helped them to respond professionally.

*"Some patients will irritate the life out of you, but, if you recognise that, then you've got more chance of dealing with it in a professional way."*

<div align="right">Interview 59, Consultant</div>

### 4.6.2 Behavioural responses to patients and their care

Comments about how staff responded to confused older patients were made by two thirds of research participants. Participants described their own and their colleagues' various behavioural responses to confused older patients. These included the need to be very patient, to think carefully and deliberate their own actions. With experience staff developed an 'instinctive' awareness of when things were likely to escalate. Many reported the practice of not approaching 'aggressive' patients alone wherever possible, but recruiting the help of a colleague. It was recognised however, that on rare occasions confused older patients could be very challenging to care for, and the best course of action when overcome by this whilst actually dealing with a patient, was to withdraw immediately and to ask colleagues for their support.

Staff reported that 'humouring' or 'colluding' with patients' delusions was disapproved of, but they nonetheless found it helpful and thought it made patients more comfortable.

The majority of participants' comments in this category referred to 'negative' behaviour they had observed in relation to the care of particularly challenging confused older patients. These varied from staff trying to treat them just like any other patient, struggling and not knowing what to do, panicking, shouting back at patients, being 'sharp' with them, delaying attending to them (because they would take time, and therefore were best left to the end) or avoiding them. A consultant suggested that this patient

group might get ignored because they cannot complain about what is happening to them.

> *"...sometimes, it's to ignore them, sometimes it's to do the bare minimum, sometimes you do see people losing their temper... I think neglect sometimes happens."*

<div align="right">Interview 59, Consultant</div>

In terms of assessment and treatment, doctors found that communication problems made it harder to make diagnoses and explain about treatments. It was also observed that when patients were very agitated, basic observations or procedures might be avoided which could lead to a lower level of care. There might also be a reluctance to insist on invasive procedures, particularly those that might be distressing.

There were many references to the need not to try to deal with these patients alone, but to recruit colleagues to help.

### 4.6.3 Emotional responses to patients and their care

Staff's reports about their own emotional response to the care of confused older patients were made by just over half of research participants. At various points in their interviews, staff mentioned how caring for confused elderly patients made them feel.  References were made to feeling daunted, challenged, sad, upset, worried, demoralised, hopeless, scared, anxious, and sorry for patients and their families. Two staff referred to occasions when they have wept. Mention of staff distress was common.

In respect of their perceived gaps between the care they were able to provide, and the care they would have liked to see provided, they described feeling guilty, disgusted, appalled, dehumanised, and torn.  But by far the most common description of this particular situation was 'frustrating'.

Some staff inured themselves to the fact that it was impossible to respond to all expressions of patient distress. Eventually they became hardened to it.

> *"When you hear people shouting 'Help' and you hear it for the first time, your immediate reaction...is you want to help them.  But actually, you can't keep responding to people's distress if they're at it all of the time... you have to put a barrier up."*

<div align="right">Interview 40, Consultant</div>

### 4.6.4 Job satisfaction and rewards

Views about job satisfaction (or more often, job dissatisfaction) in relation to the care of confused older patients were given by the vast majority of participants. Staff expressed the view that it could be difficult to experience a sense of satisfaction working with these patients because of their complexity, the subtlety of improvement, and the sheer amount of demand placed upon them.

Nonetheless, the rewards of the work were felt in different ways, by the various staff groups. Healthcare assistants felt rewarded by seeing the patients clean and happy. Physiotherapists felt rewarded when they got co-operation with rehabilitation. Nurses felt rewarded seeing patients appreciate the time spent caring for them, or seeing patients decide to eat.

Junior doctors felt rewarded seeing a very sick patient recover and finally be discharged home. Trainee specialist doctors were rewarded by having the time to engage properly. Consultants were rewarded by being able to advocate for the patient.

### 4.6.5 Psychological well-being at work

Staff's views about their own psychological wellbeing, stress and exhaustion in relation to their work with confused older patients were given by just under half of research participants. The staff who were most verbal about their experience of stress and challenges to their psychological well-being were nurses and healthcare assistants. Nurses described the experience of feeling stressed and exhausted. This was attributed either to the sheer physical and mental demands placed upon them, or to their frustrations and worry about not doing their job as well as they would like to, and not being able to do as much for these patients as they felt they should.

The demands of caring for these patients were also described as being upsetting for some student nurses, one or two of whom were described as becoming very stressed, tearful, phoning in sick and not turning up for work. The other group of staff who expressed stress-like reactions to caring for these patients was junior doctors, worrying that they may have missed something important, or feeling pressure to treat patients in ways they were not comfortable with.

> "It does actually feel very stressful sometimes at night, and that's I think when you feel pressure to sedate patients unnecessarily and you feel like the job's much more difficult at that point."
>
> Interview 55, Junior Doctor

## 4.7 Ward environment

### 4.7.1 Physical environment

**Ward characteristics**

Comments about problematic conditions in the ward as a working environment in which to care for confused older patients were offered by just under half of research participants. Many staff commented on the ambient conditions on a typical acute ward that presented challenges both for older confused patients and, directly or indirectly, for the staff caring for them. These included bright fluorescent lighting, noise (alarms, telephones, and radio), difficulties maintaining an appropriate temperature and the impersonal clinical nature of the environment. Frequent reference was made to the need to help patients orientate themselves, find their way back to their own allocated space after visits to the bathroom and toilets.  Better signage, labels, the use of different colours, distinguishing features or 'landmarks' and personalisation would help.

Nurses found it was difficult to barrier-nurse a patient with dementia in a side room (if they were frequently climbing out of bed) as they could not be easily observed.

**Ward layout**

Staff had strong views about the importance of ward design for the care of confused older patients. Comments were made by over half of them, with a high degree of consensus. Many staff found the space and layout of acute wards unsuitable for these patients.  Although ward layouts varied slightly, the agreed difficulties in most of them included not enough space around the beds for equipment (hoists, chairs, lockers, wires, zimmer frames, rotundas, and commodes) or physiotherapy and exercises. Suggestions about improved space and layouts that might improve patient mood, make staff's working day easier and would go some way towards compensating for lack of staff, were common. A frequent complaint was that there was not enough distance between beds, but too great a distance between some of the further beds and the nurses' stations, where patients were situated out of eye-line.

Staff found helping patients maintain privacy difficult under cramped conditions. Minor changes such as a small increase in the length of curtain tracking were suggested. A physiotherapist noted that when curtains were pulled around already small spaces, patients might feel 'towered over' or claustrophobic.  Toilets were often described as too few, and too far from patients' beds.  Occupational therapists also found assessing patients for toilet transfers was difficult in cramped conditions.  Improvements in general housekeeping were suggested.

## 4.8 Ward-based resources

### 4.8.1 Provision of activities on the ward

Just under half of research participants, largely nursing staff and healthcare assistants, offered views about the importance of providing suitable activities for confused older patients. Most staff who commented on this said they did not have sufficient time to sit and talk with patients and to encourage them to engage in activities. Many were concerned for patients and were worried about the psychological effects of sitting by their beds for prolonged periods with nothing to do.

> *"We haven't got any stimulation for them.  It's just, it's very sad.  It's awful really, because the mind is allowed to just stagnate."*

> Interview 3, Staff Nurse

Some recalled former times when they did have the capacity to do this, and when volunteers used to play a valued role. The general provision of materials on wards (board games, puzzles, and televisions) and entertainments (bingo, singing, dancing) was thought to be poor. It was suggested that going off ward for activities even if only for a short period each day would help staff greatly. Very often the provision of activities on the ward was linked to a place in which to do them.  The availability of a day room was regarded as important, as is discussed in the next section.

### 4.8.2 Ward facilities and equipment

The majority of research participants offered views about the adequacy of ward facilities and equipment with regard to their care of confused older patients. Both a dayroom and a dining room were thought to be very helpful for staff managing confused patients, for encouraging social interaction among patients, and for increasing their patients' confidence toward discharge. Some commented that patients appreciated these opportunities for interaction and made friends on the ward.  But such facilities had often been transferred for other usage (storage, offices).

Various other facilities and items of equipment were mentioned as potentially helpful on a busy ward with confused patients such as toilets, toilet seat raises, handles in toilets, walk-in showers, low beds, electric beds, hoist scales, an exercise bike, manual sphygmomanometers, communication aids. These were often in short supply. Occupational

therapists noted that few wards had equipment useful for discharge planning, and physiotherapists noted similar restrictions in their activities.

## 4.9 Organisational factors affecting staff

### 4.9.1 Patient location

**Unsuitability of the acute care setting for patients' needs**

Over half of research participants offered views about the unsuitability of the acute setting for confused older patients' needs. All professional groups expressed strong views, but particularly doctors and nurses. Participants commented that an acute ward was unsuitable for older confused patients and that their prolonged stay on the ward once their acute surgical or medical needs had been dealt with, caused problems for them, for co-patients and for staff.

The importance of good decision making at the point of entry to the hospital, of sending patients to an appropriate location on first admission was recognised. Suggestions were made as to what that location might look like.

> *"If they could have ...a unit designed specifically for these kind of patients, so they'll have a really different type of ward and not even a ward... open areas, little garden patch, wide spaces, big open day rooms, music playing, staff trained to deal with these kind of patients, that'd be a good service for these kind of patients."*

<div align="right">Interview 46, Trainee Specialist Doctor</div>

Several staff queried whether for some conditions confused patients might be better off nursed in an environment specialising in dementia, rather than on a busy acute ward where it was difficult to maintain calm conditions but where they were left alone with little to occupy them. The challenge of combining confused patients' care with that of very sick patients was a matter of common concern. Where patients remained on a surgical ward for longer than expected, operations were cancelled due to a lack of beds.

The general view was that there needed to be a much greater focus on the impact of mental health problems across the hospital and that every effort should be made to send patients to a suitable ward on first admission. In terms of discharge, elderly patients with mental health conditions who were no longer physically ill should not remain on acute wards while arrangements for them after they leave hospital were sorted out. It was suggested they should be placed on a more suitable 'mental health' ward where, as one occupational therapist offered, 'they really know what they are doing', although it was understood that moving to a new environment is

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particularly stressful for these patients. As one doctor commented, the 'social sort out' (referring to all management beyond the immediate medical stabilisation of the patient) was the biggest problem they faced.

**Hospital as a hazardous environment**

A third of the study's participants, the majority being doctors, viewed the hospital as a hazardous environment in which to care for confused older patients. The overwhelming consensus here was that the acute wards were dangerous places for confused older patients. Patients were often frail and/or wandered, placing them at increased risk of falls on hard floors, and knocking into ward equipment. They usually stayed on the ward longer than other patients, putting them at risk of iatrogenic problems.

Doctors referred to deep venous thrombosis (DVT), pulmonary embolus (PE), urinary tract infection (UTI), chest infections, methicillin-resistant *Staphylococcus aureus* (MRSA), diarrhoea and bed sores as examples of such iatrogenic conditions, all of which caused distress and discomfort, extended patients' stay yet further, and some of which endangered their lives.

A fall sometimes resulted in patients needing an operation, moving to yet another ward, and being in hospital for a very long time, notably because rehabilitation (compliance with physiotherapy and occupational therapy) with confused patients is a complex matter.

**Avoiding admissions**

Avoiding admission of confused elderly patients to acute hospital wards was a subject that was raised by a small number of research participants, mainly doctors. The view was expressed that some older patients who were admitted to hospital need not be there in the first place. Some are described as having no acute medical needs, but may be on the ward because they or their family could no longer cope.

> *"You see a lot of inappropriate admissions to hospital, which ends up being detrimental to the patient. They'll come and then get sick here, pick up an infection from here, when they never needed to be in ... in the first place."*

> Interview 46, Trainee Specialist Doctor

A view was offered that some referrals originated due to a misunderstanding of what hospitals can provide and a 'reflex reaction' to send them in. In such cases it was important to move such patients out of the hospital environment as quickly as possible so as to avoid unintended and undesirable consequences.

Several staff referred to the pressing need for a co-ordinated system for management of such patients in the community.

## 4.10     Staffing and staff support

### 4.10.1     Staffing establishment

Almost all the staff interviewed offered commentaries about the inadequacy of the number and type of staff available to care for confused older patients. The majority of all staff groups felt that there were not enough staff overall to deal adequately with the care of confused older patients in hospital, especially at night.

> *"My personal view is generally, staffing levels are poor: Very understaffed. Out of hours... quite ridiculous, to be honest. I just don't think it's safe for patients."*

> Interview 46, Trainee Specialist Doctor

Most participants offered 'more staff' as the single change that would most improve their working lives with respect to this patient group   Even in cases where the staffing establishment on the ward was felt to be satisfactory, there was a lack of spare capacity. Matters soon became difficult in the event of staff sickness absence (itself mentioned as a big problem), annual leave, maternity leave or secondment (for example, to a 'winter pressure' ward).  Some reported that agency staff had been unreliable and there were moves to reduce the amount of agency cover.

Although there were calls for all types of staff, the overwhelming agreed view was that the type of employee whose input would be most appreciated, and would make the most difference, particularly for nurses, would be healthcare assistants (auxiliary nurses).

### 4.10.2     Out-of-hours provision

Half of the staff interviewed commented on the difficulties they experienced with out of hours support for their care of confused older patients. There was some discrepancy between nurses and doctors' views.

The overwhelming consensus from healthcare assistants and nursing staff was that coping with confused older patient 'out of hours' (nights, weekends and bank holidays) was extremely challenging, firstly because there were fewer nursing staff on the ward, and secondly because the support required in the event of difficulty was not available. There would typically only be two trained nurses on a ward at night, with two healthcare assistants.

Some acknowledged that without the 'hustle and bustle' wards can be quiet out of hours, but when problems arose it could be difficult. During the day, nurses reported that if they found themselves in a 'funny situation' they

could go and find someone to help. But out of hours, the only recourse for help would be security. Faced with difficult situation, staff found themselves in need of senior support, and in the absence of such advice, were often distressed.

*"They don't want to do nights because they feel that they're not supported.  Especially if they've got a bad experience …they need counselling for it... "*

<div align="right">Interview 16, Staff Nurse</div>

Nurses reported that whereas they used to have senior cover on the ward, a 'Night Sister' and/or a junior doctor familiar with the patients, they now had to use the centralised system for calling a doctor ('Hospital at Night'). At the sharp end, nurses reported that the doctor on call was usually enormously stretched, could be very tired, and might not know the patient and even be reluctant to do anything without the 'regular' doctor's advice. The system was also perceived not to give a high priority to any mental health issues. However, the system seen from another perspective, that of doctors, was thought to work well.

*"'Hospital at Night' co-ordinates and …delegate jobs to juniors and, so you're less pressured, I think and you can structure things... I think it's a very positive thing…"*

<div align="right">Interview 36, Trainee Specialist Doctor</div>

However, doctors acknowledged that looking after these patients at night was particularly difficult and that nursing colleagues bore the brunt of it.

### 4.10.3    Formal staff support services

Formal support services for staff were mentioned very rarely. Two participants, both of whom belonged to nursing groups, mentioned formal staff support services in relation to their care of confused elderly patients.

References to formal staff support services centred on their role after incidents of violence from patients towards staff. Many of the staff interviewed had experienced or witnessed violent and aggressive acts from confused older patients. They seemed to deal with this largely through informal support from their colleagues and line managers. One mentioned the Occupational Health department in reference to accessing counselling, after being attacked by a patient. Another commented that although counselling was available, it was not always clear how to access it.  There were no examples in the interview data of staff providing an evaluation of formal staff support services.

## 4.11 Communication and teamwork between professional groups

### 4.11.1 Teamwork

The quality of teamwork among the various professional groups employed to care for the needs of confused older patients was discussed by nearly all of the study's participants. This was the second most common category of coded utterances. By and large, the overall view was that communication and teamwork with regard to the care of confused older patients was successful among the nursing staff and healthcare assistants on the ward. Therapists based off the ward experienced difficulties keeping informed. Nurses felt that doctors did not communicate with them well. The whole system was complicated by the lack of a single and coherent set of records for each patient. The benefits of multi-disciplinary team (MDT) meetings in those wards where they occur were appreciated by many as being helpful for speeding up processes and even avoiding unnecessarily long stays. The following paragraphs summarise the more detailed view from each group.

Physiotherapists and occupational therapists both remarked that teamwork worked well within their professional groups. They felt that some doctors were overly focused on medical fitness as a criterion for discharging patients, without consulting others for their professional opinion. Physiotherapists commented that they needed to be highly proactive to remain 'in the loop' with regard to information from doctors and nurses. Barriers to good communication included: not being ward based; having separate paperwork and patient documentation; and not being involved in multidisciplinary ward rounds. Both commented that the presence of a discharge coordinator on wards was beneficial to patients and helpful for them.

Healthcare assistants were largely positive about the nature of teamwork between healthcare assistants and nurses. Shift handovers were mentioned as a key area for the successful management of confused patients, with approximately half of references to handovers being positive in nature, and half being negative.

Nurses reported that teamwork among themselves and healthcare assistants was very good, as it was with occupational therapists and physiotherapists. Having competent and approachable nurse managers was regarded as critical in fostering a good environment for teamwork. Although some nurses acknowledged variability between individual doctors, most made reference to poor teamwork and communication between doctors and nurses. For example, nurses were not always informed of decisions made during clinical ward rounds. Nurses also commented positively on the benefits of having a discharge coordinator (a band 3 clerical post) attached to a ward. Roughly half of the references made to handovers by staff nurses

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described handovers as sufficient or good, with the other half suggesting that handovers were inadequate or problematic.

Ward managers and deputy ward managers also felt teamwork on the wards was good. The issue raised by both as being a potential area for improvement in team work was communication with and from doctors. Ward managers sometimes found it difficult to 'track down' doctors. Shift handovers were believed to work well and the presence of a discharge coordinator and multidisciplinary ward rounds were viewed as having a positive influence on ward work. In addition, deputy ward managers felt that they were providing adequate support for junior colleagues. Ward managers also noted the difficulties working with non ward-based staff, and communicating with other wards and units within the hospital. The clear majority view from all types of staff was that the presence of a discharge coordinator saved a great deal of nurses' and doctors' time.

References to teamwork from junior doctors tended to be very positive, especially regarding nurses, discharge coordinators and allied health professionals. There was also an acknowledgement from junior doctors that doctors could be hard to contact by nurses. The major teamwork issue highlighted by junior doctors was the importance of access to specialists and supervision from consultants. Where supervision was not readily available, junior doctors mentioned feeling under pressure and lacking experience. Where present, multidisciplinary team meetings were described as being beneficial, while procedures that were separate for doctors and other healthcare professionals, such as handovers, were described as unhelpful.

Trainee specialist doctors were concerned about the lack of centralised information, recognised the value of MDTs, but also the logistic challenges of making sure they happened. When they were 'out of their depth' with confused patients on an acute ward and needed advice, contact with specialists was welcome but advice from their own consultant was not always forthcoming as 'they don't deal with these kinds of issues'. Consultants and speciality doctors talked favourably about multidisciplinary team meetings, where they happened, and acknowledged that wards where these meetings were normal practice were better suited to care for the needs of elderly patients with dementia.

Consultants also talked favourably about the presence of discharge coordinators. A major issue relating to teamwork for consultants focused on difficulties where staff were not ward-based, and contact with mental health specialists. In addition, it was acknowledged that mental health issues may not always be formally noted down and the fact that different groups of healthcare professionals kept separate sets of notes did not help communication.

There was also a lack of liaison reported between the professionals in the hospital about patients' discharge.

*If there was an earlier planning, then we would know that we could probably not send these patients to their own homes because of the fact that they're not safe.*

<div align="right">Interview 60, Trainee Specialist Doctor</div>

### 4.11.2 Wider healthcare team

Half of the interviewees offered views of the role of colleagues in the wider hospital that were also involved in the care of confused older patients. Staff varied in their experience of how well colleagues in the wider hospital handled the demands of confused older patients. Most mention was made of porters, security, radiographers and phlebotomists. By and large, the experience was positive, although there were reports of some inadequate behaviours, largely attribute to lack of training, or lack of experience. Nursing staff explained that where a patient was confused and needed to go off ward (for example, to x-ray or theatre), they would go with the porters. Some porters were very competent and could handle such patients alone. Security staff were perceived to vary in how quickly they could attend an emergency situation, and their presence was reported as both helpful and unhelpful, depending on the patient. Some were calmed by their presence whilst others appeared to be more 'wound up'. And finally phlebotomists and radiographers also were perceived to vary in their skills with confused older patients. Some needed an experienced nurse with them to explain procedures to the patients and keep patients calm. It was pointed out that all these staff needed to be advised that these patients were confused, that if they did their job as they normally did it with other patients, confused patients may well end up 'getting cross'.

### 4.11.3 Specialist support within the hospital

Opinions about quality and availability of support from colleagues within the hospital who specialised in the care of older patients and patients with mental health problems were given by two thirds of interviewees. Timely access to advice and support with particularly difficult cases from specialists was reported as being difficult to achieve.

The role of geriatricians, orthogeriatricians, psychiatrists, old age psychiatrists, dementia specialists, psychiatric nurses and 'special nurses' or a 'sitting' member of staff (recruited to provide 'one-to-one' care) was perceived as invaluable.

Many comments were made by all professional groups that fast (electronic referrals) to a specialist team, with a single point of referral, would be very

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valuable. And the appropriate team should be involved at a very early stage, particularly on surgical wards that have a lot of elderly patients.

*"We need more specialists when we want them, if that makes sense"*

<div align="right">Interview 43, Trainee Specialist Doctor</div>

### 4.11.4 Professionals outside the hospital

Comments about the importance of quality and availability of professional support outside the hospital were made by two thirds of interviewees. This was a common theme in relation to both admission and discharge.

Staff expressed concerns about confused older patients' admission to and discharge from the hospital: these largely centred on links with the community. Concerns about entry focussed on lack of information, be it from a nursing home, from families, or from social services. Some homes provided no details about the care of the patient or about what is 'normal' for them, whereas others send the patients with an information sheet. Staff find the latter very helpful as caring for and treating patients with no knowledge about their home situation was very challenging.

Issues around patients' discharge also presented challenges for staff. A frequent comment was that patients were on the acute ward for much longer than was demanded by their medical needs whilst waiting for 'social sort out' and the interactions that were required with care homes, families, community psychiatric nurses, general practitioners, and particularly with social services. Ward-based discharge co-ordinators were very much appreciated.

It was reported that medical staff also have to deal with the issue of disagreement between various parties as to the best move for a patient.

*"Sometimes working out a mismatch between what social care wishes to provide, feels should be provided, and what the relatives wish to be provided can be challenging."*

<div align="right">Interview 59, Consultant</div>

The upshot of delay was that confused patients could no longer need hospital based medical intervention but typically remain on the ward for several weeks waiting for arrangements to be finalised, increasing their chances of acquiring infections and developing other complications. A view was expressed that addressing concerns about social services was one of the major issues that would reduce admissions and length of stays.

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## 4.12  Ward and hospital systems

### 4.12.1  Schedules and targets

Opinions about schedules and targets related to the care of confused older patients were offered by just over half of the study's participants. Comments in this category related to visiting times, meal times, washing, pressure on beds, discharge and audits. While certain routines like observations and drug rounds were perceived as clearly necessary on a strict interval basis, there were suggestions that slavish adherence to certain routines was not helpful.  For example, nursing staff commented on variations in 'rules' as to whether all patient washes had to be completed first thing in the morning. Imposing such routines on confused older patients, who often needed more time than other patients was thought to be unhelpful. There were variations in practice between wards.

There were mixed view about visiting times. Whilst some staff found relatives were helpful with confused older patients, others found that where patients needed quite a bit of attention, visitors could be disruptive to ward routines and thought cutting visiting hours down would help, particularly after lunch when patients liked to rest. The consensus was that restricting visiting times would help.

*"Visiting times can be a problem…Nursing staff feel that … the relatives are just as demanding as the patients a lot of the time …"*

Interview 8, Staff Nurse

Protected meal times were discussed by a few participants. There was concern that relatives could be helpful in feeding confused older patients, and banning them from the ward during mealtimes was not useful. On the other hand, it was appreciated that discouraging medical staff's interactions during that period increased the chance of patients eating well, although it may conflict with doctors' routines on occasion.

Pressure on beds on the ward was an issue. Targets elsewhere in the hospital impacted on ward staff. When confused older patients arrived on the ward with little warning, it could be challenging.

Targets for occupational therapists were reported as recently changed; one reported that a patient's discharge date was often planned before they were consulted.

*"I just think there's an extra pressure on... already we're doing the minimum that's safe for people... because often, the discharge date planned before … But there's just so much more we could do...if we had more people to provide that service."*

Interview 38, Occupational Therapist

Participants particularly ward managers, commented on the amount of time required to undertake audits, fill in questionnaires and complete associated paperwork.

### 4.12.2    Patient documentation

Issues relating to documentation and paperwork for confused older patients were cited by over a quarter of research participants as being problematic. Although all professional groups commented, the majority of concern was expressed by nursing staff. Participants highlighted their views of the limitations of current conventions for keeping patient records. These concerned the quantity of paperwork, and duplication.  The need for paperwork was understood, but the extent of it was questioned.

*"If you've not written it then the saying is it hasn't happened."*

Interview 12, Staff Nurse

Several different sets of notes were kept by different professional groups (nurses, doctors, therapists) and these notes were not available to all.  Staff reported that an increasing amount of paperwork reduced the amount of time they could spend providing direct care to patients, and some reported that they found this to be frustrating. Several doctors commented that issues relating to mental health often were not included in formal medical notes at all. There was a suggestion that a 'single entry' computerised system, with an electronic folder for each patient, would reduce duplication.

### 4.12.3    Hospital, Trust and NHS management issues

Finally, issues relating to the wider hospital management and Trust were mentioned by about a third of participants. Some of the comments in this category were related to targets, as described previously. Staff expressed frustration with the wider hospital management in terms of pressure to discharge patients home before they are ready, a lack of suitable places for 'convalescence', inadequate time to get the area cleaned before the next patient arrives, pressure to have patients from outside the specialty 'sleep out' in wards, the lack of continuity of medical teams on wards, pulling staff off wards with minimal notice and no consultation to assist on other wards, and token consultation about staffing issues. A&E four hour trolley wait targets, and having to see patients within 24 hours of referral were mentioned on several occasions as pressurising.

Staff acknowledged the support of their ward managers, but noted that 'their hands are tied from above'. The fact that a new senior manager was 'coming out onto the wards to do shifts' was welcomed by nursing staff. Token consultation by managers was an irritant.

*"You are being consulted but you're just not being listened to … To me, it's patronising.  You might as well not bother in the first place."*

<div align="right">Interview 3, Staff Nurse</div>

A consultant recalled a time when geriatricians used to come to the Admissions Unit to advise. It was suggested it would be very helpful for healthcare of the elderly specialists to pick up the confused older patient group on admission, streamline their next move, and determine a care package. The deleterious effects of moving confused older patients from ward to ward was mentioned on several occasions throughout the interviews. The interconnection of systems and their complexity were highlighted, as was the need for review.

*"The systems in place sometimes need overhauling...just need someone to sit down... and see how can we make this more efficient."*

<div align="right">Interview 46, Trainee Specialist Doctor</div>

## *4.13      Chapter summary*

This study presents the summarised views of a representative sample of healthcare staff on wards in a typical UK general hospital. Staff were frank and honest in sharing their experience and offering suggestions for improvement. The evidence presented in this report testify to success and failure, both on the part of staff, and on the part of the system in which they work. Staff of all grades and within all professional groups identified key issues with regard to education and training, staff support and occupational satisfaction, the hospital environment, interdisciplinary communication and organisational systems that impacted on their ability to provide care for confused older patients.

# 5 RESULTS OF OBSERVATIONAL AND INTERVIEW STUDY

## *5.1        Outline of findings*

Findings from this study, drawn from observational or interview data, were initially grouped around the confused older patient, their family caregiver and the co-patients. Data from all three groups also produced insights into the experience of staff in caring for the confused older patient and thus staff were created as a fourth group.

Observation: The study involved 72 hours of non-participant observations of care on 45 occasions on 11 wards of the study hospital including surgical, orthopaedic, health care of older people, stroke, intensive care and general medicine.  Most observation periods lasted between one and two hours, (range 45-180 minutes)

Interviews: The observations were complemented by 35 formal interviews after discharge and concerned the experiences of 34 confused older patients. Interviews were conducted in patients' homes with family caregivers and with the patient present and taking part, wherever possible. In addition, four co-patients that did not have confusion but had shared a four- or six-bedded bay with a confused older patient were interviewed after discharge.

The mean age of the patient participants was 86.8 (range 70-99); 19/34 (56%) were female; 21 (62%) were widowed, 9 (26%) were married, 2 (6%) had never married, and 2 (6%) were divorced. Sixteen had previously lived alone, of whom 6 returned, 8 were discharged to a care home, and 2 died (carers were interviewed). Eleven had previously lived with family, of who 5 returned, 4 went to a care home, and 2 died. Seven had previously lived in a care home, 3 died and the remainder returned. The range of diagnoses recorded in case notes was: dementia 22, depression 4, delirium 1, alcohol 1, and anxiety 1.

The relationship of 32 of the carers to the patient was recorded: wife 9, daughter 8, son 7, niece 2, female friend 2, sister 2, son-in-law 1, and grand-daughter 1. The mean age of carers was 63 (range 46-79), and 24/34 were female. Of interest, 15 carers disclosed one or more mental health problems of their own.

The findings elaborated a *core problem*, 'disruption from normal routine', and a *core process*, 'gaining or giving a sense of control to cope with disruption'. Both the core problem and the core process resulted in immediate, short term and longer term outcomes.

All names of people or places are pseudonyms to preserve anonymity.

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## 5.2 The core problem: disruption from normal routine

### 5.2.1 Description

The essence of the problem facing the hospitalised confused older patient was the 'disruption from normal routine'. The problem of disruption from normal routine could be used to understand the experiences of all involved in the study: the family caregiver; the co-patient who shares the ward space in hospital; the staff who care for them as well as the confused older patient. From all these perspectives, when a confused older patient was admitted to hospital there was disruption from what normally happens: behaviours and responses were different and often unanticipated, routines were broken and the consequences of this were difficulty and distress. Synonyms for the verb *to disrupt* exemplify disruption as it occurred for all those involved, these include: to interrupt, upset, disturb, create disorder, unsettle, agitate, discombobulate, interfere with, break up, disorganize and disconcert (92).

The disruption typically began prior to admission, when the confused older patient deteriorated or had an accident or event precipitating admission. Setbacks in hospital, and beyond, gave rise to further disruption. It took some time for a new equilibrium to be established.

The core problem gave rise to the core process, which was how the various players coped with the core problem. The response to disruption was to seek control, order, coherence, clarity and calm.

### 5.2.2 Patients

Familiarity and routine are key elements of daily care for confused older patients, when it is chronic such as in dementia . Maintaining a familiar environment and avoiding or planning carefully for changes in routine is helpful (93). Hospitalisation produces a rapid disruption to routines. There are changes to surroundings and unfamiliar people doing unfamiliar things. In the following interview extract, Sally summed up the importance of routine to her mother:

> *"She's now settled, it took her two or three days, but getting her back into the old routine that she had, because with Alzheimer's they've got to stay in a routine, that's the most important thing, that's the only thing they feel comfortable with, is keeping them in a routine, so going to the hospital was out of her routine.."*

Sally, daughter of Victoria

### 5.2.3 Carers

The disruption for the family carer looking a person with dementia was similar to that of the confused older patient.  If the person was cared for at home then routine became the norm for the whole family, the day's activities meted out by the needs of the confused older patient. Hospitalisation disrupted these routines. It also caused emotional disruption to family carers because of uncertainty about the patient's illness and prognosis, and the worry of whether they were frightened, in pain, hungry or unable to make themselves understood. The disruption caused by hospitalization was more than simply visiting a loved one in hospital:

" *I felt on the point of nervous breakdown and I can remember feeling as though my head was just going to explode with the worry of it, you know, you've got the stress of seeing your mother dying … I was having to go to the hospital every other day, we took it in turns, my sister went one day and I used to go [the next]."*

Brian, son of Hannah

If there has been a previous hospitalisation, the caregiver often used that experience to anticipate changes in the confused older patient's behaviour and the longer lasting effects of disruption on the confused person:

*"I mean because I've also experienced some dreadful, dreadful times with my husband, how he was treated, and a lot worse than my mum, believe me…"*

Bernice, daughter of April

### 5.2.4 Co-patients

For many co-patients, the disruption to routine and some degree of indignity was usually rationalised given the need for medical and nursing care. Many found camaraderie with other patients, but expected to have some privacy and to be safe despite the public nature of ward areas. These expectations often remained unmet when they shared with a confused older patient, because the usual etiquette of patient and visitor behaviour was challenged. In the following quote, a co-patient with his wife, Valerie, described his misinterpretation of the "normal" sign on the board above his bed, which in fact referred to his diet:

*"When the people took me in to [the ward], there's a board at the back of you and … I noticed it said on my board, normal didn't it Valerie, it said*

*normal, and yet I was the only one that said normal, and we wondered what that was… We realise now, it was people with dementia and people with problems that they were having to contend with, in fact a couple of nights they took the bed down to where the nurses were because of disturbing the rest of us, you know what I mean."*

<div align="right">Anthony, co-patient</div>

### 5.2.5 Staff

Hospitals require routines to ensure that important tasks are performed, and the needs of patients with confusion made it difficult:

*The lady in bed 2 stood up.  The nurse responded 'Sit down; I'll come back to you'.  The nurse went away and the lady stood up again and started to walk, pushing the table to support her. When the nurse noticed her, she approached her 'Where are you going, where do you want to go?  This is not a good idea – you are not really safe.' A colleague gave the lady her frame so that she was no longer using the table.  Eventually, the nurse said 'Let's take you back to your bed.'  'Where are we going?' 'We'll take you back to your bed and change your nightie because it's dirty'.  At this point, the male patient who was helping with the menus appeared to attach himself to the lady and the nurse.  The lady commented 'I don't want him with me', 'He's alright, he won't harm you'.  The lady tried to push him out of the way and he then tried to hit her in response.  The nurse called the man's name and tried to use calm authority to get him to stop...  Another nurse noticed what was happening and intervened to take the male patient out of the way.*

<div align="right">Field note, ward observation</div>

## 5.3      The disruptors

### 5.3.1 Overall description

Three key disruptors that predisposed, precipitated or perpetuated disruption were found:

- the added complexity when physical and mental illnesses interact
- attitudes to confused older people
- limited capacity of the system to respond appropriately to the confused older patient.

The routines of confused older patients and their carers were disrupted and they in turn disrupted both the hospital staff and the co-patients. In the following sub-sections, Tables 6-8 present the summary of the code structure for each of the disruptors. Each column of each table represents the codes structure by group. Throughout, column 1 refers to the impact on or actions of the confused older patient; columns 2, 3 and 4 similarly refer to the impact on or actions of the family carer, the co-patient, and the staff respectively.

### 5.3.2 Complexity of the combination of physical and mental illness

For all parties, the combination of acute physical illness along with the chronic confusion associated with dementia and the acute confusion of delirium caused greater disruption. Table 4 presents the code structure for this category.

Table 4. **Complexity of the combination of physical and mental illness.**

| Disruption to the confused older patient | Disruption to the family carer | Disruption to the co-patient | Disruption to hospital staff |
|---|---|---|---|
| Delirium | Not being the person they were | Having to cope with the behaviour of confused older patient while also dealing poor health | Greater 'juggling' of patients and relatives |
| Making sense of being in hospital | Unsatisfactory visiting experience | | Some issues are just too complex |
| Not wanting hospitalization or treatment | Disruption to community services upon admission to hospital | | |

**Confused older patient**

In addition to the change in routine causing sudden confusion, the confused older patient was often unable to rationalise the need for hospitalisation. Disorientation due to the displacement in hospital was compounded by delirium and the combination often precipitated argumentative, aggressive behaviours:

*"She was a bit upset, mum was coming out with a few things that were a bit...! I've never got me mum speaking to me like that before! She was accusing me of kicking her out and all sorts of things, and it really upset me, and [the nurse] said "your mum's not talking normally", she said "she's not normally like this"? I said, "no". She said "it's because she's got this water infection". But I mean I really didn't know how vicious they could be … she said, "Oh no it can be very nasty."*

Lucy, daughter of Freda

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The confused older patient often tried to make sense of the situation and created elaborate explanations for their experience as Eric's daughter, Tina related in her interview:

> *"I think towards the end two or three of them did start talking to my dad, because he said "this is an airman's ward you know, belongs to the forces" …I said, "Oh right". So he said, "brave lads there are you know", I said well dad if it's the Air force (because me dad was in the army) how come they've let you in here?  "I'm privileged, I'm very, very honoured", he said, "but the only reason they've let me in here is because I was a paratrooper and I used to jump out of their planes"… He was convinced he was in a military ward, and they all worked for the forces, even the nurses and that."*

> Tina, daughter of Eric

Despite the humour often found in the stories, the disruption did cause distress to the confused older patient. Fear of unfamiliar people and places along with unfamiliar and sometimes painful procedures caused the patient to want to go home and never to return to hospital.

> *"…my mum was terrified … [she'd say] "I don't like it here" … I think she was a bit bewildered when she first was there, she was sitting on the edge of the bed, didn't know why she was there, didn't know what was happening, every day we went, [she said] "are you coming to take me home?"*

> Jill daughter of Betty

**Family carer**

Hospitalisation caused disruption from the generally calmer routine of home or nursing home. The disruption was exacerbated by the illness itself. Delirium, when present, and the general change in behaviour of the patient when hospitalised caused consternation and distress for many family carers. Many of them were aware that their relative would become disruptive in hospital, for others it was their first experience leading to shock and embarrassment.

> *"Well he completely changed when he was in there: completely. It sent him even more wappy [crazy] than what he was when he went in.  He wouldn't let you touch anything, if you went anywhere near his clothes or anything he'd scream at you, LEAVE THEM ALONE, THEY'RE MINE. And you had to... I mean he'd be wet, he'd wet his clothes and everything, and to take them home wash he'd be screaming at you..."*

> Martha wife of Ralph

This change continued after discharge where he tore the house apart looking for something, saying, when Martha had asked him what he was looking for: "I'm looking for my life". He had become a very different

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person; a change Martha attributed to both the acute physical illness and the hospitalisation.

One of the issues that perpetuated the sense of disruption and frustration was the unsatisfactory nature of visiting patients in hospital. The lack of any comforts such as adequate numbers of chairs and access to refreshments was also a source of dissatisfaction.

> *"Two till eight I think it was [visiting times] … It was hard to get chairs to sit down; there's definitely not enough seating for visitors. Even if there's just two or three people getting visitors … there's no seats for anybody else. And you don't want to plonk yourself on the bed"*

<div align="right">Sally, daughter of Victoria</div>

One significant cause of disruption for the family carer during hospitalisation was the worry that community services already set up would be lost by the time their relative returned home. This problem was described by Brenda who was valiantly trying to minimise disruption in the long term by keeping the same caregivers at home but she could see this was not going to happen:

> *"Another problem was the social services terminated her care package after a fortnight in hospital regardless of what I'd said, and I was keeping in very close contact, keeping them informed. I was very concerned that she should stay with the same carers because she had a relationship with them, they're doing very personal things for her and it worked really well, and I knew she was on, on the brink of not being able to stay at home…"*

<div align="right">Brenda, daughter of Helen</div>

### Co-patient

Disruption relayed from co-patients was a complicated emotional response because on the one hand they recognised the need for the confused older patient to be in hospital but on the other hand sometimes found their presence very frightening leaving them feeling out of control, as described by one co-patient:

Anthony:   *"As I said most of my time rest is part of my healing, I couldn't rest because I was frightened, you know, what's going to happen next."*

Valerie:   *"They gave you a buzzer one night didn't they?"*

Anthony:   *"Oh yes, I had an emergency buzzer put on me just in case, you know… they realised after the first night, the second night they put this emergency buzzer on me so I could call somebody straightaway. But I didn't call them for normal things, but only when he began to shake things about."*

Valerie:   *"When he was pulling the things off the front of the bed, wasn't he? And throwing them all over the place."*

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Anthony, co-patient and Valerie, his wife

**Hospital staff**

Staff described the disruption of having a confused older patient on the ward as leading to greater 'juggling' of patients and/or relatives needs. The following quote is from a staff nurse:

*It's the relatives and the falls. We have to reduce the number of falls but to do that you'd have to keep them occupied … [they should] ask relatives to give 1:1. We can't give 1:1. And I get really upset when I see a fall. I feel it's my fault. Even if I've done everything else, I feel it's my fault.*

Field notes during observation

### 5.3.3 Attitudes to confused patients

Attitudes to confused patients were found to be mainly negative in all groups. Table 5 presents the code structure for this category. While most of the data came from family carers, most of the comments, and therefore the number of codes, are about the staff. However, the staff's own perspectives were not part of this study, and are given in Chapter 4.

**Table 5.  Attitudes to dementia**

| *Confused older patient* | *Family carers* | *Co-patient* | *Staff attitudes* |
|---|---|---|---|
| Unforgiving of the behaviours of other confused older patients | Unforgiving of the behaviours of other confused older patients | They should be somewhere else | Where dementia is advanced, lack of reciprocity in relationships |
| | Comparing other confused older patients to their relative | | Infantilisation from some members of staff |
| | | | Lack of understanding or knowledge of dementia |
| | | | Staff are ageist |

**Confused older patient**

There were limited data from observation and interviews with the confused older patient on their attitude to dementia itself and to others with the condition. One patient with dementia during observation complained bitterly about the behaviour of other confused patients:

*[Derek] agrees to my observation and conveys to me that he is very bored and lethargic in hospital. This he puts down to a lack of sleep because of*

*night time disruption by the patient adjacent to him. Derek is fed up with this patient and states: "he is just a total pain, no idea what he is doing".*

<div align="right">Field notes, ward observation</div>

The noise and general disruption from other confused older patients were noted by family carers who related the experience of their relative:

*"Oh, she didn't like it, she says "she's waking me up all the time through the night", she's says "I can't stand it", she's says "I wish she'd shut up". She says "I keep shouting through the night, shut up, shut up". Oh dear."*

<div align="right">Alma, daughter of Patricia</div>

### Family carer

The attitudes of the family carer toward other confused older patients were similarly unforgiving at times. This included complaints and generally comparing the behaviour of other patients to their own relatives.

*"…I mean she was no bother compared to her in the next bed, oh dear…"*

<div align="right">Alma, daughter of Patricia</div>

### Co-patient

Co-patients, when discussing the situation in hospital, were often very annoyed at the disruption caused by sharing the ward with a confused older patient. There was recognition that staff were doing their best or that the hospital was short of beds but the disruption nevertheless brought out negative attitudes:

*"Well personally I think the same as everybody else in the ward, we couldn't damn well sleep, he would sort of wander around in the night and come right up to you in the bed."*

<div align="right">Mike, co-patient</div>

### Staff

The staff's attitudes described here, except for the first code regarding lack of reciprocation in relationships with confused older patients, were generated from the perceptions they had given the family carers who were interviewed. With regard to reciprocation, the following quote makes the frustration clear that there is no reward:

*There is no reward. I mean, you can't ask for reciprocation...kids give something back....even those on intensive care come back and are pleased to be alive. Well most of them. I know they are still people, but in a way they have no way of putting back what you [give them].*

<div align="right">Field notes, conversation with staff nurse during observation</div>

Infantilisation of the confused older patient was noted in staff attitudes as illustrated by the following example when a patient was scolded for being incontinent:

*Whilst the relative is seeking out a member of staff, the lady promptly uses the chairs as a toilet and diarrhoea seeps over her legs and onto the floor. A staff nurse rushes toward her and scolds her with, "Emily, what are you doing? Look at the mess. You must use the toilet not the chair. All the men can see you"*

Field notes, observation

Many times family carers expressed the opinion that staff at all levels did not have the right training or experience to care for someone with confusion. Family carers thought that was because it was a general hospital but even then they would have preferred to have a specialist nurse or team to advise the staff on how to manage their relative. The lack of knowledge was portrayed in several ways. For example one family recalled a doctor's attitude to pain management:

*"…we were told by the doctor that people with dementia don't feel pain as much as somebody who hasn't got dementia."*

Kirsty, granddaughter of Florence

Recognition of the lack of training was made by co-patients as well as family carers. Richard's wife, Doreen, commented on the lack of understanding of the nurse on this occasion:

*"...there was one gentleman like messing about with the door, he was waiting for the door to go open, and I was trying to make a conversation and the nurse was like, "oh he'll be alright, just leave him". And I was like, well that's not the approach you know, they're in there, you're supposed to be looking after him, if you don't know about dementia then you shouldn't be in that particular job. ...I know it's a hard thing to deal with, but there must be some set guidelines somewhere."*

Doreen, wife of Richard

The difficulty of caring for someone with dementia or confusion during the disruption of hospitalisation was clearly recognised. Family carers also noted a general ageism in the system which they found hurtful and distressing. As Bernice stated in her interview:

*"And it doesn't matter how old she is, she's still my mum..., this is an awful thing to say, but I think it's true, it's an ageist thing, you know you shouldn't be so worried about somebody that's nearly 97 because they've had their life, that's the attitude."*

Bernice, daughter of April

### 5.3.4 Capacity of system to respond to people with confusion

The third category of disruptors was the system itself in the sense that the family carers found the inflexibility of the system caused unnecessary disruption in their ability to help care for their relative. There were two explanations for the inflexibility: dementia and delirium are problems but not a priority in the general hospital, and the difficulties caused by the hospital environment itself. Table 6 summarises the code structure.

**Table 6. Capacity of the system to respond to people with confusion**

| Impact on the confused older patient | Impact on the family carer | Impact on the co-patient | Impact on the staff |
|---|---|---|---|
| Dementia and delirium are problems not a priority | | | |
| Care not organised for confused older people | Lack of clarity regarding diagnosis of dementia | | Hospitals are concerned about measurable outcomes rather than the softer issues |
| | A lack of flexibility when dealing with family carers of confused older people | | Lack of time to deal appropriately with confused older people |
| | It is difficult to find out what is going on | | |
| Environment | | | |
| The chaos of the emergency department | No-one knows you | | Concerns about patient safety |
| Lack of continuity – being moved from bed to bed or department to department | Lack of continuity – being moved from bed to bed or department to department | | |
| Threats to personal dignity | | | |

**Inflexibility: patient with confusion**

The crux of the problem with the system from the perspective of the confused older patient is that the organisation is not able or interested to cater for their particular needs. This idea overlaps with other codes such as lack of training and understanding of dementia and delirium. For example, Edwin's wife felt that staff might not recognise the differences in confused older patients and therefore couldn't respond appropriately.

*"I don't know whether that ward is geared up for dementia patients or whether it's just geared up for old people, certainly some people clearly had got dementia... but some people just looked poorly.... they must have all sorts of jobs on to try to deal with everybody,.. and maybe the staff don't differentiate between old and frail and dementia, maybe they don't know well enough to [differentiate]."*

Felicity, wife of Edwin

The low priority of dementia care was starkly revealed to Florence's daughter when she tried to have her mother moved to a ward where she thought they might know more about dementia:

*"I rang up and spoke to social services section at the hospital...I believe there's a ward down here, it's a dementia ward ... and they said try requesting it to the sister on [your mother's] ward. So I did and she said, "No, we're here to sort out her physical condition not her mental condition, we can't do that."*

<div align="right">Erika, daughter of Florence</div>

The ward was not the only place where the low priority of dementia care led to greater disruption, it also occurred in the emergency department where so many of our participants had negative experiences:

*"I don't think the emergency room is equipped for people with mental problems either. There was another gentleman there that kept calling out and one nurse walked up and said, "you're going to have to go if you keep this up". But that means nothing to somebody with a mental impairment, there needs to be a different way of handling it."*

<div align="right">Sally, daughter of Victoria</div>

**Inflexibility: family carer**

An element of the low priority of dementia care was evident in the frequency with which staff did not know whether or not patients had cognitive impairment. As a consequence family carers sometimes lacked trust in the staff to take care of their relative:

*"I wrote it down; I actually wrote it for the nurses because they didn't believe what I'd said that he could change so much from going into hospital and how he was when he came out. But he doesn't fail the mental test, now you tell me, he can answer every question that they ask him for the mental test, but he's definitely not normal…"*

<div align="right">Amy, daughter of Ralph</div>

**Inflexibility: staff**

From the perspective of the respondents who were mainly carers, there was a low priority of dementia care among staff because of the perception of a target driven culture in the NHS, leading to lack of time to be flexible in the delivery of care. As Brenda noted when discussing this:

*"They've got to reach the government's target, and they were making her fit the theory."*

<div align="right">Brenda, daughter of Helen</div>

During one observation the plethora of charts and posters describing how the ward was meeting targets was very obvious to the researcher who commented in her notes:

*Are the patients in the way of something bigger? Is it about producing statistics? The audit charts on the wall tell a story of goals met and accountability. How do you measure humanity? Are those statistics more important than sitting down and having a chat with Frank?*

<div align="right">Field notes, reflection following ward observation</div>

The time consuming nature of caring for the confused older patient was often cited as a reason for poor care. As one staff nurse related during an observation:

*It's most difficult for all of us when we are really busy. It's like walking on hot coals, because you have to make decisions and the ward is chaotic with a person shouting or being very disruptive. And they need just as much care but in a much different way. I have to try to keep my patients alive and so have to learn to cut out the chaos of somebody wandering and being aggressive.*

<div align="center">Field notes, conversation with staff nurse during observation</div>

The following quote from a discharge coordinator who let off steam with the researcher during an observation demonstrates how all these elements of disruption (the time consuming work, the lack of clarity of diagnosis) affect her and her work.

*I dread dealing with them. They never go right. Always disruption, change of plans, something goes amiss. The paid carers (community services) can be brill [sic] and will make sure it's all in place but that's if they have been going in already, especially if the patients have nobody else in this world. But new discharges, I just groan as I expect disruption and difficulties. The medical team won't agree to put down a diagnosis of dementia, even though it's staring you in the face, and yet won't refer to a specialist. So I can't get extra funding and then the care home manager comes and sees how confused they are and request more money. It's a round and round the houses, if you forgive the pun, so on this acute ward they sit. It's wrong really.*

Field notes, conversation with discharge coordinator during observation

**Environment: patient with confusion**

From both the perspective of the confused older patient and the family carer the environment did not lend itself well to the management of distressing behaviours. The chaos of the emergency department was described by many participants. The time taken to process patients through the system clearly exhausted confused older patients and caused further disruption through discomfort and lack of consistent attention.

"...*when she went in she was very confused, we stood there for absolutely ages… I got there before lunch…and [we] did not get into the ward until*

*half past 10 at night, and that in itself was an experience because she was very tired, very worn, and it does take it out of them."*

<div align="right">Bernice daughter of April</div>

**Environment: family carer**

In addition to the wearing process through the emergency department, family carers felt that it was expected they care for their relative continuously. Many family carers felt it was impossible to leave their relative even to go to the toilet because they knew their relative would become distressed and/or disruptive. This took a great toll on family carers:

*"I couldn't, no, if I'd have left her and she'd ...decided she'd get off the trolley she would try to get off the trolley, and you can't walk away and leave someone that you know is going to do something more to hurt themselves, you just can't do that."*

<div align="right">Bernice, daughter of April</div>

Family carers' also worried about the impact their relative's more challenging behaviour might have on the care received and outcomes. The next quote demonstrates how cracking down on unacceptable behaviour from certain quarters of society can be misinterpreted by those caring for a confused person.

*"Yes. And there's all these signs up there, that they won't tolerate aggressive behaviour, you know you will be asked to leave! And I'm thinking, oh my god, you know, they're going to kick her out of here!!"*

<div align="right">Sally, daughter of Victoria</div>

**Environment: staff**

The environmental discussion raised in the data with regard to the staff centred on two issues: falling and medications. The medications issue was raised by family carers several of whom noted that pills and tablets were found untaken by their relative when they came to visit. They were concerned that staff were not watching patients take their medication.  The interpretation being that staff clearly expected patients to take their medication and didn't alter their routine for the patient who was confused.

*"Twice my daughter went under his bed to pick up all the tablets under his bed, so he obviously wasn't taking the medication. Unless they actually stood there and made sure he took it, he wasn't taking it. … a two or three year old would have picked those up, they were all nice colours. And that did worry us."*

<div align="right">Tina, daughter of Eric</div>

With falls, the staff were concerned about sedating patients to reduce calling out and aggression but this increasing the risk of falling.

Furthermore, there was a risk to themselves as this nurse related in a conversation during an observation.

*The nurse admits to reaching out and physically trying to stop people fall. She states this is against the policy of the NHS but would rather do this than see her patient injure themselves: "you just do it" and gestures with both arms as if catching midair. The others agree. This opens up a discussion about the views of wandering, falls and getting work done.*

Field notes, ward observation

## 5.4 The core process: a sense of control to cope with disruption

### 5.4.1 Description

The core process represents the basic social psychological process at play in the experience (86). All four groups (patient, carer, co-patient and staff) were attempting to gain a sense of control for themselves or give control to others. The purpose of gaining a sense of control was to minimise the impact of the disruption caused by the admission and hospitalisation. Feeling in control was an important outcome. Members of all four groups displayed both emotion-focused and problem-focused strategies, in tune with those proposed by Lazarus and Folkman (94).

Four uses of the verb *control* helped define the term with respect to the core process (95):

- to restrain self and emotions – to hold one's emotions in check, be calm, be professional, feel safe or protected

- to have power over – to influence or direct care or interactions

- to monitor – to check, supervise, regulate and verify

- to restrain – to limit, contain or keep in check unwanted activities or behaviours

The following sections describe the actions taken to gain or give a sense of control by each of the four groups. The staff actions come mainly from the viewpoint of the confused older patient, family carers and co-patients and from the analysis of observations of care, rather than from the staff themselves. Actions giving or gaining a sense of control were negative as well as positive in relation to the care of the confused older patient. Some actions demonstrated self-preserving coping strategies, whereas others showed a desire and ability to promote control in others. Whatever the motivation, all interactions had some consequences or outcomes indicating whether the action minimised or perpetuated disruption.

## 5.4.2 Actions: confused older patient

As described in the methods, the observed behaviours of confused older patients were interpreted by taking a person-centred stance. Using this approach, confused older patients behaved in a way that might help give them a sense of control and create a sense of control for family carers. There was little or no evidence of actions by confused older patients that gave a sense of control to either co-patients or members of staff. Confused older patients gained a sense of control through four categories of behaviour: constructive, disengaged, distressed and neutral behaviours. A number of different actions and behaviours were observed within each category. These are summarised in Table 7.

**Table 7. Actions by confused patients to gain or give a sense of control**

| Gaining a sense of control for the themselves | Giving a sense of control to the family carer | Giving a sense of control to the co-patient | Giving a sense of control to the staff |
|---|---|---|---|
| Constructive behaviours:<br>• Sociability<br>• Showing their personhood<br>• Inquisitiveness<br>• Form relationships and attachments<br>• Trying to take control<br>• Being assertive<br>• Resisting<br>• Purposeful activity<br>• Gathering other people's belongings<br>• Work like activity | Expressions of concern for the family carer | | |
| Disengaged behaviours<br>• Exposure<br>• Prolonged inactivity | Trying to negotiate drinks for the family carer | | |
| Neutral behaviours<br>• Causing disruption<br>• Disinhibited use of language<br>• Wandering | | | |
| Distressed behaviours<br>• Aggression<br>• Agitation<br>• Challenging the system<br>• Crying<br>• Muttering and moaning<br>• Shouting | | | |

### Constructive behaviours

Constructive behaviours occurred when the confused older patient responded in a positive way to aspects of their stay in hospital. It is possible that the other parties might not have considered the behaviours to be positive due to the negative impact on them. However, they appeared

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to be associated with some degree of purpose or positive interaction on the part of the patient with dementia. These behaviours seemed to fit into three broad categories: those involving elements of sociability, those where the confused older patient tried to assert a degree of control over what was happening and those where they seemed to be acting in a purposeful manner, even when the exact purpose of the activity was not obvious to the observer.

There were a number of ways in which confused older patients acted sociably. When approached, Charlotte appeared to demonstrate a clear sense of her own personhood:

*This meeting cannot be considered an observation since Charlotte was simply not going to have that. I was in her room and she hung onto my hand and chatted almost continually for the whole 90 minutes. She was genuinely interested in my work... although the conversation was very tangential.*

Field notes, Ward observation

On a number of occasions, patients appeared to seek companionship even when their communication skills were more limited. During a ward observation, Dean and the man in the next bed seemed to spend a considerable time together, even though it was far from clear that either of them could converse coherently

*[Dean] got into bed with assistance. Once he was in bed, the neighbour got up and moved Dean's slippers and sat in the chair right next to Dean's bed. He continued talking to Dean occasionally nudging him.*

Field notes, Ward observation

Similarly, there was a clear sense that some of the study participants with confusion appeared to form strong bonds with others. Amy described the fondness that her father felt for one particular nurse:

*"He'd got one nurse that he thought the world of and he said "She's my favourite, she's definitely my favourite, she loves me, you know, she would do anything for me."*

Amy daughter of Ralph

By contrast, Derek tried to appeal to an outside source when he was unhappy with the care that he was receiving:

*Derek is fed up and tired, he is also fed up with having no working telly and his mobile phone has been locked away by the charge nurse.....this it transpires is because he phones for the ambulance in the night when he doesn't get seen quickly enough by the nurses.*

Field notes, ward observation

There were a few examples where people seemed to engage in purposeful activity, although it is likely that this caused problems for members of staff and other patients. Amy reported that her father spent much of his time in hospital gathering other people's belongings:

*"The second time (in hospital) he was calm and collected, and the only trouble was at night time he went round pinching everybody's stuff, he'd got more combs, more toothbrushes, more teeth!! ...He'd been round all their cupboards and helped himself to their things."*

<div align="right">Amy, daughter of Ralph</div>

### Disengaged behaviours

Disengaged behaviours tended to occur where the confused older patient appeared to be unaware of the people around them and, as a result, engaged in behaviour that either compromised their dignity or well-being. The sense of control comes from the patient behaving as they want albeit without regard for those around. We observed numerous occasions where the confused older patient exposed themselves without appearing to be aware of it. One such example was described by a co-patient:

*"..undress and dress himself, and try to put his pyjamas bottoms on the top part of his torso, all sorts, he was totally out of control really... he really didn't know what he was doing."*

<div align="right">Mike, co-patient</div>

Another indicator of disengagement seemed to be where the individual had prolonged periods of inactivity, particularly when there were things happening that might have been expected to capture their attention. However if this activity was perceived as threatening then the person with confusion may withdraw in order to feel safe. During an observation, Raymond was sitting at a desk at the end of the bay on the ward:

*Raymond sat at this desk for about 30 minutes … at this time there was quite a bit of cheerful chatter between the staff, patients and relatives in this bay but his body language and facial expression appeared to indicate that he was not watching or listening to it or that he was in any way interested.*

<div align="right">Field notes, ward observation</div>

### Distressed behaviours

Distressed behaviours were those that appeared to indicate that the confused older patient was suffering in some way and attempting to make this known. This might simply involve expressions of distress such as crying or rocking or it might include stronger responses such as agitation, aggression or even accusation. Jean, a co-patient, commented that she was relieved to be in a side room rather than on the open ward because she

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would have been kept awake at night because a few other patients who had dementia were crying. Similarly, during an observation, Lesley spent a lot of time muttering to herself, apparently in distress:

> *"Oh dear God, help me please. Help me God." A little while later she muttered "Oh God, let me go home."*

<div align="right">Field notes, ward observation</div>

Bernice experienced a much stronger reaction of distress from her mother as a result of being in hospital. The sense of control in this case can be interpreted as fighting back in response to the threatening situation in which the confused older patient found themselves:

> *"She turned violent, she said "I don't want to be here, what they're doing to me is not right, and you shouldn't have brought me in," and I said, "But I didn't bring you in mum," and she got her stick …and she raised it up and they had to press the button, because she was going to hit me with it. Which she'd never done anything like that in her life."*

<div align="right">Bernice, daughter of April</div>

Similarly, Phyllis was expressing her distress in accusations at the hospital staff. The sense of control being that she was trying to make her voice heard:

> *I was told by the senior staff nurse caring for Phyllis that she was more upset than usual because the doctor had told her going home was not possible until a psychiatrist had seen her. This had upset her and she was now accusing the staff of keeping her in against her will and thinking her "mad".*

<div align="right">Field notes, ward observation</div>

**Neutral behaviours**

Neutral behaviours were those that might have made sense to the confused older patient but tended to have the potential to be more troublesome to other people. They differed to constructive purposeful activity in that it was unclear that the activity was expressing purposefulness on the part of the individual. Typical neutral behaviours included wandering, causing disruption by interfering with other people or possessions and disinhibited use of language. One such example was described by Doreen who, when visiting her husband Richard encountered a woman who appeared to be wandering without aim:

> *"There was one woman I felt sorry for her because she was walking up and down and she said nobody wants me but she was going in the ward she was picking thing up looking. Sometimes she'd put them down then she'd perhaps walk a few steps then she'd come back and put it down again."*

<div align="right">Doreen, wife of Richard</div>

One example of disinhibited use of language was described by Vernon in relation to his mother:

*"The other thing that I got from my mother and this is obviously age, she never used to swear, but profanity was starting to come into her language! And you'd wonder where it had all come from."*

Vernon son of Beryl

**Actions to give a sense of control to family carers**

Some of the confused older patients attempted to take actions that might be interpreted as giving a sense of control to their family carers.  These actions included expressing concern for the welfare of the family carer and trying to negotiate or promote their comfort. Alma spent a long time in the emergency department with her mother Patricia.  She felt she needed to stay with her because her mother was on a trolley in the middle of the department and Alma was concerned that she might try to get off the trolley and fall:

*"Even when I was standing next to her she'd say, "I bet your legs are really hurting you, because I couldn't stand all that time".   And then she'd say to me, "Would you like to go and have a drink?"."*

Alma, daughter of Patricia

### 5.4.3 Actions by family carers to gain or give a sense of control

Family carers appeared to take actions to give a sense of control to all four of the identified parties involved in the hospital stay. Family carers influenced the core process for the confused older patient, in addition to seeking control for themselves. The family carers were acutely aware of the impact their relatives had on the ward including the co-patients and staff. In general their actions tried to shield co-patients and staff from disruption. The actions and strategies used by family carers to gain or give a sense of control are outlined in Table 8. Family carers attempted to give a sense of control to the confused older person in two main ways: by acting to counter the inadequacies of the system and by trying to maintain the personhood of the confused older person.

**Table 8. Actions taken by the family carer to gain or give a sense of control**

| Giving a sense of control to the confused older patient | Gaining a sense of control for themselves | Giving a sense of control to the co-patient | Giving a sense of control to the staff |
|---|---|---|---|
| Actions to counter system inadequacies<br>• Advocacy<br>• Filling in major gaps in care<br>• Using detailed knowledge of the person to influence nursing care | Actions to promote coping and change<br>• Monitoring the quality of care<br>• Complaining and questioning<br>• Coping by becoming expert<br>• Strategising to achieve desired outcomes<br>• Seeking support in order to provide care<br>• Getting things organised while the patient is in hospital | Looking out for the co-patient | Supportive attitude<br>• Blaming the system not individuals<br>• Expressing support for nurses |
| Actions to maintain the personhood of the confused older patient<br>• Showing warmth to the patient<br>• Providing occupation<br>• Promoting dignity for the patient<br>• Maintain the link with normal life<br>• Substituting for them | Coping by putting things into perspective<br>• Playing down the seriousness of events<br>• Supporting the NHS and its staff<br>• Blaming the system not individuals<br>• Supporting the NHS<br>• Supporting the nurses<br>• Rationalising behaviour that might be viewed as challenging | Keeping the patient occupied | Supportive actions<br>• Delivering care to help the nurses<br>• Keeping the patient occupied<br>• Getting involved with co-patients |

## Countering the inadequacies of the system

Three main strategies seemed to be used by family carers to counter the inadequacies of the system: advocacy; using their knowledge of the person to influence care; and getting involved to fill the gaps in care left by the hospital staff and system. Mary found that she was in a position where she had to advocate on behalf of her mother when the hospital system seemed to be a little slow in working towards encouraging the mobility of her mother following a significant fracture:

> *"I was trying to push everybody to get her on her feet, get her back to the care home, given they weren't going to operate..."*

> Mary, daughter of Gillian

There were several occasions where it seemed to be clear that family members had a better understanding of the needs of their relative than did the hospital staff. Susan was very concerned that the staff did not appreciate the importance of regular bowel movements to her grandfather:

> *"And I said, "Well if any of you had really been bothered to ask me …if my granddad don't go three times a day there's something the matter with him. My granddad is a regular bowel mover, and he's not been."*

> Susan, granddaughter of Paul

Occasionally family carers noticed essential elements of care were not being offered by hospital staff and found they had to fill the gaps. Brenda had significant concerns about the quality of support for personal hygiene offered to her mother:

*"... it wasn't until then that she was fit enough really to go into a wheelchair [for a bath] and for me to do it but up until then, she would have needed a hoist which they have wonderful facilities [on] the ward but no evidence that they were in use."*

Brenda, daughter of Helen

**Maintaining the personhood of the confused older patient**

In addition to monitoring their relative's progress through the hospital system, family carers also took actions that appeared to be aimed at preserving the personhood of the confused older patient during their hospital stay. They did this by showing warmth at moments of stress, keeping their relative occupied, respecting the dignity of the person and trying to maintain their link with normal life. These actions appeared to give the confused older patient a sense that they were someone other than just a hospital patient. Bernice found the emergency department a challenging environment for her mother. As a result, she did what she could to comfort her:

*"The trolleys really are side by side so you really haven't got much room at all … I stroked her hair and made sure that she was alright."*

Bernice, daughter of April

Boredom and having nothing to do emerged as common themes for all patients. It presented a particular problem for confused older patients, when out of their usual environment; they seemed to have great difficulty finding ways to amuse themselves. When visiting her husband Sidney, Diane met the granddaughter of the patient in the next bed who was determined to address this deficit and so gave a sense of control to her grandfather:

*"...he had a granddaughter … and she was fantastic ... she said "Let's go and see if we can find some dominoes or cards," and she went and they said, no, they'd got nothing. And she came back and she said, "I'm going to bring my own tomorrow."*

Diane, wife of Sidney

Some family carers were particularly concerned about the dignity of their relatives. They expressed this by their perception of how their relative should be spoken to. George and his wife, Janet, were very keen that Albert, George's father, should be treated with respect:

*George:*   *"We don't mention dementia in front of him, we just say he forgets and we leave it at that. So because of that I try to get*

*away from him to see the nurse, rather than talk in front of him. You feel sometimes it's like when you had kiddies, but you don't want to feel like that because it's your dad you know."*

Janet:  *"We just want to be kind, and not patronise him."*

George, son of Albert, and his wife, Janet

For some the sense of personhood was enhanced by the receipt of cards and visits from family and friends.  Trevor, found the receipt of cards very important:

*"[The cards are] very important. Any sort of communication with the outside world and with friends and it was so lovely to have... to know... people have recognised that and thought of you."*

Trevor, patient

**Family carers gaining a sense of control for themselves**

Family carers used a number of strategies to feel better able to cope. The first of these was monitoring the quality of care as they felt their relative could not be relied upon to provide an accurate picture of the care they were receiving. This sometimes involved questioning staff directly to obtain the full picture. Jill sensed that members of staff would leave family carers uninformed if they were not asked questions:

*"I asked the questions … and my mum was, "Oh you shouldn't be asking all these questions, you know. "  Yes, I should, because I won't be told anything unless I ask the questions."*

Jill, daughter of Betty

Some family carers gained a sense of control by taking the initiative to inform themselves about their relative's condition through other sources while other family carers deployed certain strategies to achieve their own goals. Francesca demonstrates the latter by adjusting her visiting plans to avoid giving the impression that she would be available to support her aunt on a day to day basis:

*"I remember at the beginning I wanted them to... realise that she's on her own, she's got carers, they came in three times a day, but we weren't there, in real life we weren't there every day, we weren't there every two days because we couldn't get up there all that time, we weren't really any use to her …"*

Francesca, niece to Bettina

For some family carers, the admission to hospital provided an opportunity to prepare for life following discharge.  Tina explained she was able to use the time when her father Eric was in hospital to make his home safer:

> *"While he was in hospital I had his gas turned off to his gas cooker because at night time he was turning all the gas on and forgetting what he was going to do, and wasn't lighting it and was going to bed."*

<div align="right">Tina, daughter of Eric</div>

The second strategy employed by some family carers to gain a sense of control was rationalising what was happening. This may have enabled them to trust the staff caring for their relative. Putting things in perspective was done in three main ways. Firstly this was achieved by playing down the seriousness of events that happened. Such a strategy was generally employed when family carers encountered what they perceived to be deficiencies in care or communication. When Helen was admitted to hospital, her daughter did not realise she had had a heart attack and was not informed of this for some time. However, Brenda rationalised whether knowing would have made any difference:

> *"They were approachable and I can't really complain other than, I did feel a bit concerned that I hadn't been told that she had in fact had a heart attack. But, as I say, there were no serious consequences of me not knowing."*

<div align="right">Brenda, daughter of Helen</div>

Avoidance of assigning blame to individuals working within the healthcare system with acceptance of the limitations of a large organisation appeared to be a second way to put things in perspective and helped family carers cope with their experiences. Tina explained that hospital staff had responsibilities to numerous people not just her and her father:

> *"I mean my dad is the most important person in that room to me, but to them that's working there they've got everybody, not just one."*

<div align="right">Tina, daughter of Eric</div>

The third way noted to put things into perspective was when families sometimes rationalised their relatives' behaviour to gain perspective on the situation. Doing this, sometimes, made it seem less unusual or troublesome. John reflected on an occasion where his mother became aggressive and concluded that it was a reasonable response to a situation she would not have liked:

> *"My mother got a bit confused, and … it's the only time, [laughs] she got a little bit aggressive... I was having to answer the questions because she wasn't really … So I think being talked across didn't suit her much."*

<div align="right">John, son of Dot</div>

**Family carer giving a sense of control for the co-patient**

Family carers promoted a sense of control for co-patients in two main ways. Firstly by looking out for co patients while they were visiting. Alma found

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she had to summon the nurse to deal with other patients while visiting her mother:

*"When others were ringing and ringing and ringing for a nurse, there were none coming, you know, or you couldn't find anybody, you went to try and find them yourself."*

<div align="right">Alma, daughter of Patricia</div>

Secondly, family carers distracted their relative during visits, the net result usually being that the confused older patient was more settled and less disruptive to co-patients. Mike commented on this:

*"Well obviously he was occupied with them [visitors], you know, until they left, and then he was off again."*

<div align="right">Mike, co-patient</div>

**Family carer giving a sense of control for the member of staff**

Family carers tried to help the staff cope with their relative in two ways. These were with their attitudes and with their actions.

It is probable that the expressions of support for the NHS and its staff by family carers raised earlier helped carers give themselves a sense of control also gave a sense of control to members of staff. Where family carers were blaming the government and other agencies for shortcomings in care, it removed the spotlight from hospital staff. Brenda targeted her criticism at government targets:

*"I mean … they're under pressure to get patients out, aren't they? They've got to reach the government's target, and they were making her fit the theory. And I just thought … it's the system isn't it? It's not necessarily the staff."*

<div align="right">Brenda, daughter of Helen</div>

Meanwhile, Diane expressed clear support for nursing staff:

*"I don't know how they cope. We used to say [this] when we walked out after visiting some nights … some of the nurses would say "Well I'm going at 7 o'clock and I'm glad!" I said I'd be glad for you as well. I felt sorry for them. It's a big responsibility."*

<div align="right">Diane, wife of Sidney</div>

Some family carers took particular actions with the specific goal of being supportive to hospital staff. These actions included deliberately spending more time with their relative to reduce the demand on the time and attention of nursing staff, as Felicity pointed out:

*"… he was up and down the ward walking around and I think they (the nursing staff) found this quite troubling. So if I could sit with him and try and get him to stay put that was something for them."*

Felicity, wife of Edwin

Sometimes this support extended to helping provide care to their loved one or by offering support to co-patients. Alma described calling a nurse to help the co-patient of her mother:

*"I mean one lady got out of bed herself and fell over. Oh no, here's me running to get a nurse "quick she's fell out of bed." Oh dear."*

Alma, daughter of Patricia

### 5.4.4 Actions by co-patients to gain or give a sense of control to cope with disruption

Given the level of disruption experienced by co-patients it is not surprising that co-patients needed to take actions to gain a sense of control for themselves. However, there were examples of co-patients also giving a sense of control to the other three identified parties involved in their hospital stay (Table 9).

**Table 9. Actions by co-patients to gain or give a sense of control**

| *Giving a sense of control to the confused older patient* | *Giving a sense of control to the family carer* | *Gaining a sense of control for themselves* | *Giving a sense of control to the staff* |
|---|---|---|---|
| Look out for other patients | Monitor care and report to relatives | Making the best of things | Avoid blaming the nurses |
| Include the confused older patient in visits from their relatives | | Being reasonable | Being reasonable |
| | | Trying to control the behaviour of other patients | |
| | | Aggression | |

### Co-patient giving a sense of control for the confused person

There was ambiguity in the relationships between confused older patients and co-patients. There were many expressions of discontent about being placed near someone who was behaving in a way that was perceived to be disruptive. However, there was also evidence of concern for these people on the part of co-patients. Co-patients gave a sense of control to patients with dementia in two main ways. Firstly they sought to include these patients during visiting if the confused older patient was alone. Secondly co-patients demonstrated a sense of responsibility towards the confused older

patient and were prepared to intervene if they needed assistance. Caroline, a co-patient of Mary illustrated the latter point:

*"I said "If you want anything Mary, just call me and I'll ring my bell"."*

<div align="right">Caroline, co-patient</div>

Similarly, Mike explained that the other patients in the bay would try to persuade the confused older patient back to their bed area when they tended to wander

*"You had to try to do something because the nurses didn't have time, so you know people would try to gently guide him to where he should be."*

<div align="right">Mike, co-patient</div>

**Co-patient giving a sense of control for the family carer**

Co-patients were able to offer a sense of control to family carers by being their eyes and ears on a twenty four hour basis. Many family carers stated that they were unsure of what was happening on a continual basis due to their relative's forgetfulness and lack of information offered by staff. However, on occasion co-patients were able to update family carers on what had happened to their relatives. Brenda identified a time where this happened:

*"The lady in the next bed, she said to me "Your mum… wet the bed."*

<div align="right">Brenda, daughter of Helen</div>

Similarly, co-patients informed Mary of moments when her mother's condition improved:

*"Apparently one of the girls in the bed opposite said "Oh, your mum had her eyes open this morning … she was talking."*

<div align="right">Mary, daughter of Gillian</div>

**Co-patients gaining a sense of control for themselves**

Co-patients employed both positive and negative strategies to give themselves a greater sense of control. These included trying to make the best of things and in doing so the co-patient seemed to accept that they needed to be in hospital and had no control over who they were placed beside. Being reasonable in this way seemed to allow them to retain some control over their situation. Mike acknowledged that while a co-patient's behaviour was disruptive, it was not deliberate:

*"You couldn't be annoyed with him because it wasn't really his fault."*

<div align="right">Mike, co-patient</div>

Some co-patients reacted more negatively and attempted to control the situation by being instructive and at times aggressive towards the confused older patient. The following occurred during a field observation:

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*Dean wandered into the next bay and started to tug at the equipment which was on the wall at the end of the bay.  He walked very close to bed one and the patient called out 'Get out, go away!'*

<div align="right">Field notes, ward observation</div>

**Co-patients giving a sense of control to members of staff**

Co-patients tended to use similar attitudinal strategies as family carers to give a sense of control to members of staff.  These involved avoiding blaming the nursing staff for any problems that were being experienced as a result of sharing a clinical area with someone with confusion and recognising the stress that the nursing staff were under. Jean felt that the nursing staff took too long to answer her buzzer but chose to blame the pressures they were under than the individuals in particular:

> *"Sometimes they were a long while [responding to the buzzer] because I say there's not enough staff on.  I mean they are probably looking after … these other people and that."*

<div align="right">Jean, co-patient</div>

## 5.4.5 Actions by members of staff to gain or give a sense of control

Members of staff seemed to take actions to give a sense of control to all four of the identified parties involved in the stay in hospital as outlined in Table 10. It should be emphasised that elements of these findings are particularly interpretative as members of staff were not formally interviewed. However, there were a number of brief conversations with them during the observations, in addition to the observations themselves and extensive commentary from family carers on their attitudes and performance.

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**Table 10. Actions by members of staff to gain or give a sense of control**

| Giving a sense of control to the confused older patient | Giving a sense of control to the family carer | Giving a sense of control to the co-patient | Gaining a sense of control for themselves |
|---|---|---|---|
| Use of interpersonal skills<br>• Being a cheerful and calming presence<br>• Displaying warmth<br>• Negotiating care and working with behaviours<br>• Treating the person with respect | Recognising and valuing the relationship between the family carer and the person with dementia<br><br>• Making family members feel welcome<br><br>• Exchange information with family carers | Pre-emptive separation of the confused older patient | Embracing the personhood of the confused older patient<br>• Positive communication<br>• Negotiation |
| Working with family carers to get to know the confused older person | Offering reassurance to the family carers | | Focusing on self without jeopardizing personhood<br>• Juggling<br>• Feeling OK about own work<br>• Relying on the support of co-patients<br>• Avoid working alone |
| | | | Focusing on self by suspending the personhood of the confused older patient<br>• Containing the activities of the confused older patient<br>• Avoiding, ignoring or being detached from the confused older patient<br>• Reporting 'bad' behaviour to the family carers<br>• Being officious and stand-offish<br>• Expressing impatience<br>• Unprofessional behaviour |

## Staff giving a sense of control for the confused older patient

Members of staff sought to give a sense of control to the individuals with dementia by using their interpersonal skills when dealing with them and by finding out about the person from their relatives.

Positive interpersonal skills tended to promote a sense of control for the confused older patient and the common theme that permeated a positive interaction was that the person was being treated with respect. Being cheerful and displaying warmth appeared to have a positive impact on the confused older patient. Tina recalled one such interaction with her father:

*"There was one nurse there, and she went "Hello Eric, you alright? You've got company." That was the first nice thing that we'd heard, she actually called him by his name and asked him, you know.  And then he said, "No, I'm not...I've lost another comb", and she said, "Oh I bet you've left it in the bathroom," but it wasn't, so she looked somewhere else and it wasn't there, and I said "Don't worry about it, it's only a comb … when I come tomorrow I'll bring him some more combs in." She said, "Oh I can do*

*better than that," and she come back with one, she said "I've got you a bright yellow one look, if you put that one down it'll glow at you." And he was on top of the world; he thought it was absolutely lovely."*

<div align="right">Tina, daughter of Eric</div>

When staff negotiated with the person rather than imposing their will it seemed to promote a sense of control for the confused older patient. During an observation, this seemed to be particularly successful with Clive:

*Clive then took a sweet from the lady in bed 5. He was about to eat it when the nurse intervened. She requested that he did not eat it because he had swallowing difficulties. He ignored her and put it in his mouth. A negotiation followed in which he eventually spit the sweet out and the nurse promised to get him something softer. She returned with a yogurt, which he ate.*

<div align="right">Field notes, ward observation</div>

By finding out about the person from relatives, staff also gave the confused older patient a sense of control because when nurses had more information on an individual's needs and preferences, they were better equipped to meet those needs.

**Staff giving a sense of control to the family carer**

Family carers gained a sense of control from staff when their relationship with their relative was recognised and when they were regularly updated on their relative's progress. Where family carers were welcomed onto the ward, they seemed to feel recognised and as a consequence reassured. Jill appeared comforted by the ward sister acknowledging their arrival on the ward and her willingness to update them on her mother's condition:

*"She went on to the cardiac ward and the sister was there straightaway ... she said just go into the room and wait until we've got your mum settled for the night, and then I will come and talk to you. So then she came and she chatted, and she told us what to expect, why she was there, and what was going to happen."*

<div align="right">Jill, daughter of Betty</div>

Similarly, Susan seemed to find reassurance in the kind words offered to her as she left her grandfather in hospital:

*"And then she said "Don't worry, we'll look after him" and she cuddled me because I think they could tell really that … we're just a caring family and he's like our patriarch … so she said "He'll be fine" and I said "Thank you very much.""*

<div align="right">Susan, granddaughter of Paul</div>

**Staff giving a sense of control for the co-patient**

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Nursing staff tried to give a sense of control to co-patients by moving confused older patients that they perceived as being disruptive from the open ward. During a brief conversation as part of an observation a deputy ward manager explained the dilemma she faces in trying to balance the needs of all patients:

> She [the deputy ward manager] ...says that whilst she doesn't like putting dementia patients in side rooms she can't have wandering patients with sick patients who are recovering from surgery.

<div align="right">Field notes, ward observation</div>

**Staff gaining a sense of control for themselves**

Members of staff appeared to use several strategies to give themselves a sense of control when working with confused older patients. These were clustered into three broad categories, the most positive of which was embracing the personhood of the confused older patient. The second strategy was protecting self without jeopardising personhood. The final strategy was suspending personhood of the confused older patient which reflected a way of coping with disruption that had negative consequences for the confused older patient and the family carer as well as the staff member. Embracing the personhood of the confused older patient potentially gave the staff a sense of control because they were choosing to give care that was considered to be of high quality. Generally, actions that embraced personhood were based in positive communication with the confused older patient. During a ward observation, a ward housekeeper was seen to respond to patient distress with great sensitivity:

> The housekeeper goes over to Phyllis "Phyllis, now don't cry, it does you no good love. I'll make you a cup of tea. Your husband is coming soon like he always does." the housekeeper wraps both arms around Phyllis and rocks her slowly like a child, gradually slowing until the sobbing ceases.

<div align="right">Field notes, ward observation</div>

In an effort to gain control, members of staff seemed to take actions that were not always positive for the confused older patient. The actions described within this category were not necessarily harmful to the sense of personhood of the confused older patient but the intended beneficiary of the action seemed to be the member of staff rather than the person with confusion. There were quite a few accounts of situations where members of staff had to juggle the needs of numerous patients. This tended to result in delays to care that were not necessarily the fault of the individual nurse, as illustrated below:

> The lady in bed 4 stated that she was unhappy and wanted to go to bed. The nurse explained that she would help her just as soon as she has finished with another patient [in bed 2]. Having helped sort this lady [in

*bed 2], the nurse explained to the lady in bed 4 that she needed to gather a few things before coming back to help her.*

<div align="right">Field notes, ward observation</div>

The net result of situations such as this seemed to be that members of staff had to come to terms with the notion that while the care they were giving was adequate, it was short of ideal. A member of staff verbalised this:

*It's sad as they were all people once … like real minds.  They all get good care on here but they do have to wait for it sometimes and I hate that.*

Field notes, conversation with a healthcare assistant during observation

Another strategy for coping with having to juggle care was to rely on the sense of duty that some co-patients felt towards the confused older patients. As Tina explained:

*"The nurses seemed to bring everyone together and it was a case [of] … "If you see so and so trying to get out of bed or be in distress ring your bell, will you?""*

<div align="right">Tina, daughter of Eric</div>

When staff avoided working alone they seemed to benefit from time spent with colleagues:

*Approximately eight nurses congregate around the food trolley and talk excitedly for five minutes.  Then the process of delivering food to patients begins.  There is a lot of activity at the food trolley, nurses talking and joking with each other.*

<div align="right">Field notes, ward observation</div>

The final category of actions taken by members of staff to give themselves a sense of control were those that seemed to be harmful to the sense of personhood of the confused older patient.  These actions tended to be associated with poor communication with both family carers and patients alike. There were a number of occasions where members of staff appeared to choose not to engage with the confused older patient even though an opportunity seemed to present itself. Doreen found staff officious and standoffish when she came to enquire about her husband but had not arrived during visiting time:

*" …when we got up there [to the ward] and said oh we've come to see Richard, 'oh well we can't let you in, it's not visiting hours, visiting hours is between so and so and so and so'. And I said, 'I didn't say I wanted to see him, I want to know how he is?' 'Oh well I can't tell you that'. And she said, 'would you like me to go and get somebody that can?' And I was like, "yes, please".*

<div align="right">Doreen, wife of Richard</div>

There were occasions when communication seemed to deteriorate further, resulting in curt comments or expression of impatience. On this occasion John thought he had his glasses with him when he arrived to the ward but the staff nurse (SN) thought otherwise:

SN:     *"I was here when you were admitted last night, when, you didn't have your glasses then."*

John: *"I think I did."*

SN:     *"You were very poorly, you didn't have them then, we'll have to agree to disagree."*

<div align="right">Field notes, ward observation</div>

Where members of staff had experienced difficulty with the behaviour of the confused older patient, they appeared to report this behaviour to the family carer. This did not appear to be an attempt at information sharing but rather an expression of frustration. Alma experienced this:

*"The odd time they'd say like "Oh, she's been playing up you know, she's been shouting down"."*

<div align="right">Alma, daughter of Patricia</div>

There were also occasions when it appeared that nursing staff might have been taking action to contain or curtail the activities of the confused older patient. During a ward observation, Aiden appeared to be restrained as he was placed in a position that would be difficult for him to move from.

*Aiden was sitting on a comfy chair with wheels at the nurses' desk at the end of the bay. I got the impression that he was placed in this position so that he would not stand up or fall out of the chair.*

<div align="right">Field notes, ward observation</div>

Finally, there appeared to be instances where action by members of staff seemed to be best described as unprofessional behaviour. This presented itself as either mockery or unsympathetic communication in the face of distress. During a ward observation a confused older patient became distressed when being assisted onto the weighing scales:

*He is agitated and frightened, crying with tears down his face. Not one member of staff offer any comfort or reassurance. The staff nurse tuts and reprimands him for losing more weight. The tears continue.*

<div align="right">Field notes, ward observation</div>

In another example, Albert was teased by members of staff:

*His lunch arrived. A member of staff went to fetch him from the nurses' station. While accompanying him, she commented to another member of staff 'He's just helping the doctors with their diagnosis.'*

<div align="right">Field notes, ward observation</div>

### 5.4.6 Summary of core process

In the case of each of the four groups represented in this data, the core process for each of them was taking action to gain or give a sense of control in order to cope with the disruption from the routine caused by the hospitalisation of the confused older patient. There is synergy with the problem focused and emotion focused approaches to coping as described by Lazarus and Folkman (94). In the next section the outcomes of the interaction between the core problem and core process are presented.

## 5.5 Outcomes: the consequences of disruption

### 5.5.1 Description

Outcomes were the consequences of disruption or attempts at giving or gaining a sense of control. In the immediate or short term timescale these outcomes had the potential to perpetuate disruption. In the longer term they set the scene for behaviours for the next encounter with hospital or a health care professional.  Outcomes were apparent for all four groups but the family caregiver and patient outcomes have the most evidence, because these perspectives were sought.

### 5.5.2 Outcomes for the confused older patient

The outcomes for the confused older patient fell into three broad categories: immediate responses, short-term outcomes and long-term outcomes. Immediate responses did not appear to have any impact beyond the immediate moment of response. Short-term outcomes had an impact for much of the length of stay in hospital but no longer than this. Long-term outcomes appeared to have an impact on the person with dementia at the time of the interview.  The outcomes that appeared to be experienced by the confused older patient are outlined in Table 11.

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**Table 11. Outcomes experienced by confused older patients**

| Immediate outcomes | Short term outcomes | Long term outcomes |
|---|---|---|
| Appreciation of care given | A sense of connection | Better help at home |
| Maintained familiarity | Getting sorted, at least for a short time | Getting better |
| Comfort and personhood | Exhaustion | Relief to get out of hospital |
| Disorientation | Disruption due to transport delays | Deterioration due to or even despite hospitalization |
| Fear and upset | Unnecessary stress | Disruption of discharge |
| Lonely and frightened | | |
| Boredom | | |

### Immediate responses

There was a range of both negative and positive immediate responses by the confused older patient. The more negative responses included feelings of boredom, disorientation and distress.  More positively, there was also evidence of experiences of comfort, personhood and appreciation. The feelings of boredom appeared to be linked to the limited capacity of the system to respond appropriately to the confused older patient.  This was highlighted by Amy:

*"One thing we did feel that was lacking, there was no music on the ward... it was deathly silence, there was nothing,..., so everybody was just bored, they were literally bored out of their brains."*

Amy, daughter of Ralph

Feelings of boredom on the part of the confused older patient may have precipitated certain behaviours as illustrated in the following observation of Dean:

*The student nurse took him (Dean) back to his own bed area but he did not sit down. (At his point, it seemed to me that it would have been so much better if he had something to do – the student nurse did not appear to have anything that she could use to distract him from his desire to get up and go into the next bay).  Dean returned to the next bay and again started to tug at the equipment which was on the wall.*

Field notes, ward observation

The environment was not ideal: Diane found that the ward decor appeared to add to her husband's confusion:

*"When Sidney first went in and he'd come round a little bit, he started imaginary picking things up off the floor, and very, very graciously handing them to you and saying it's not broken... these little spots in the*

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*rubber, they thought they were things on the floor.. little dots, coloured dots all over the floor … and I thought well who's chosen to put this on the floor because it's totally wrong! But I'm not complaining, no, please don't think that."*

Diane, wife of Sidney

One of the causes of fear and upset seemed to be the attitude of some members of staff towards confused older patients.  Where members of staff lacked understanding or empathy for confused older patients, they were more likely to approach such patients in a manner that would cause distress.

More positive responses such as feelings of comfort and enhanced personhood appeared to stem from both the involvement of family members in care for the confused older patient in addition to a more person-centred approach by members of staff. The latter was evident during an observation when Frank expressed appreciation to the nurse who helped him:

*'Frank, let me help you get sorted out', she takes his arm and leads him to the toilet.  She comes out to get a clean pair of pyjamas, and goes back in.  She is with him for about five minutes.  I hear them talking to each other inside the bathroom.  They emerge from the toilet and the staff nurse moves on to the next job.  Frank says in a relieved tone 'Thank you everyone'.*

Field notes, ward observation

**Short-term outcomes**

The negative short term outcomes for the confused older patient included feelings of stress, exhaustion and uncertainty, which appeared to be linked to the limited capacity of the system to respond appropriately. During the admission process, Bernice felt that the length of time spent in the emergency department left her mother feeling exhausted:

*"In A&E … I went before lunch, and my brother joined me, they stayed until about 2.30, then they left … and I did not get into the ward until half past 10 at night, and that in itself was an experience because she was very tired, very worn, and it does take it out of them."*

Bernice, daughter of April

The discharge process appeared to be a major source of feelings of uncertainty as people seem to spend long periods of time packed up, ready to go and waiting for transport to arrive.

More positive short-term outcomes occurred in situations where confused older patients appeared to have a sense of connection either with a member of staff or with a family carer.  Bernice found that she and her mother were

better placed to maintain a sense of connection with each other when professionals were prepared to intervene and encourage her mother April to make the difficult decision to move into a care home:

*"You know exactly where you are, you know what's wrong with the patient because he's (the doctor) told you, and he's told you in front of the patient, so that it hasn't come from you, and they're thinking is she telling me right, you know, it's come from somebody in authority that's said look April this is what's wrong with you, we don't think you can care for yourself, and it's all been removed from you. You can then be the support person to help her overcome the way she's feeling, you then become... you haven't made the decision, so you're in it with her, and you can support her and say if this is going to happen I'll be there for you."*

Bernice, daughter of April

## Long-term outcomes

The main negative long-term outcome for the confused older patient appeared to be deterioration as a result of being in hospital. On occasions this seemed to be an inevitable part of the disease and end of life process, whereas on other occasions family members believed that there were clear links between the admission to hospital and the decline in their relative. There were a number of occasions where family carers either saw the need to have their relative discharged from hospital as rapidly as possible or, after discharge, reflected on the deterioration in their relative that appeared to be due to the time in hospital. Mary seemed to be aware that hospital was not good for her mother and tried to facilitate an early discharge:

*"My main observation … would be that she's got over the fall and the accident but she hasn't got over the experience … my mother … is not how she was when she went in now and never will be. And, the care home and I kept saying, "We need to get her out of here"."*

Mary, daughter of Gillian

Similarly, Brian blamed the long-term physical deterioration of his mother on a hospital system that was ill equipped to meet her nutritional needs;

*"(Before going into hospital) I used to have to cut her food up, any hard food very, very small indeed, and she did prefer things like mashed potatoes and custard and so on, and in the ward, she was just kind of given ordinary food, there was no attempt to give her anything like Fortisips, say, any nutritional supplement, and anyway, they discharged her after about six or seven days back to me with care from the social services. She had deteriorated a lot and she had lost weight, and she never really started eating properly again after that."*

Brian, son of Hannah

The more positive long-term outcomes tended to relate to getting better and getting home.  Brenda believed that the long-term recovery of her mother was due to the intervention of hospital staff:

*"… the physiotherapists were very kind to her, very encouraging and they actually got her on her feet and moving again."*

<div align="right">Brenda, daughter of Helen</div>

Occasionally the negative impact of the hospital admission had a positive outcome at discharge. For Felicity, the failure of the hospital to meet the needs of her husband meant that in the long-term he settled more easily than expected into his care home:

*"I think he was probably so relieved to get out of the hospital [laughing] ... he felt very restricted there because he couldn't go out of the ward, and every time I left he was trying to get out with me, and that was very upsetting. So probably he feels more at ease now in the home, than he was in the hospital, which is a good thing."*

<div align="right">Felicity, wife of Edwin</div>

However, the relief associated with discharge was sometimes challenged by the need for readmission, as Alma explains:

*"She must have only been out, came out on the Thursday, and I think it was the Sunday she was back in again …"*

<div align="right">Alma, daughter of Patricia</div>

However, in this situation, the failed first discharge had a more positive long-term outcome as it was recognized that there was a need to increase support, which was then put in place.

### 5.5.3 Family caregiver outcomes

Family carers experienced outcomes that were immediate, short and long-term.  These are outlined in Table 12.

**Table 12. Outcomes experienced by family caregivers**

| Immediate outcomes | Short term outcomes | Long term outcomes |
|---|---|---|
| Embarrassment as a result of being involved in personal care | Frustration at system inflexibility | Anger with individuals and teams |
| Indignation due to imposition | Feelings of stress | Anger with system inadequacies |
| Reassurance as a result of monitoring | Lack of trust in the team | Discontent with inaccurate information that had long-term consequences |
| | Disappointment with relationships built with staff | Formal complaint |
| | Feelings of trust | Guilt due to inability to provide care |
| | Satisfaction with quality of information received | Feeling unprepared to meet future care needs |
| | | Reaching a fixed view of the service being of a poor quality |
| | | Reaching a fixed view of the service being of a high quality |
| | | Feelings of being supported |

## Immediate responses

The immediate negative responses experienced by family carers in this study included embarrassment and indignation. Such feelings tended to be experienced when getting involved in delivering care to a family member that was of an intimate nature, or when they felt they were being taken advantage of. Susan felt her mother was not comfortable being involved when Susan's grandfather, Paul, needed to use a urine bottle:

*"I mean it doesn't bother me … me mum was a bit embarrassed, she like turns away you know."*

Susan, grand-daughter of Paul

Mary appeared to believe that staff in the emergency department were prepared to leave her to look after her mother without considering her needs:

*"We were left sitting behind closed curtains for a very long time, and … there seemed to be oodles of staff sitting behind a desk not very far away, none of whom appeared to be doing things …, it was way past lunchtime, we hadn't been offered a drink or anything, eventually, they brought us a cup of tea but I hadn't had any opportunity to go and buy myself a sandwich or get anything for my mother to eat. Neither had I had any opportunity to go to the toilet because I didn't feel I could leave my mother."*

The more positive immediate responses experienced by family members were reassurance and satisfaction with the care that was being delivered. Susan seemed to be evaluating what she saw and found it reassuring:

*"And yeah, quite a good day really that first day … obviously they [nurses] like to make an impression don't they, they'd come in; "Are you alright Paul?" Giving him his cups of tea and everything, and everything seemed to be alright, and I felt quite alright leaving that day."*

Susan, grand-daughter of Paul

## Short-term outcomes

A number of negative short-term outcomes were experienced by family carers. In particular, they seemed to experience frustration due to the inflexibility of the system, and stress due to their relative's illness and as a result of the health and social care system. They expressed feelings of being out of control and lacked trust in the system which included disappointment with the poor quality of relationships with members of staff. Alma expressed frustration when she appeared to receive mixed messages from staff about whether or not her husband could collect her mother, Patricia, from the ward.

For Brian, the experience of his mother's illness and prospect of bereavement left him with feelings of immense stress:

*"I can remember feeling as though my head was just going to explode with the worry of it, you know, you've got the stress of seeing your mother dying."*

Brian, son of Hannah

Angus identified hospital processes that could have been potential sources of stress to others if, unlike him, they did not have ample free time;

*"I'm retired, I've got the time to phone social workers, I've got the time to go to meetings, I've got the time to go to see the doctor on the ward, but a lot of people who are working, if that had been their mum, that would have been incredibly stressful for them."*

Angus, son of Hilda

In other situations, there was a sense that the system appeared to function without listening to or considering family carers, leaving them feeling out of control. Brenda described how the team made plans for discharge without apparently engaging in anything more than tokenistic consultation with her:

*"We had a family meeting, and it was decided that she should go back home, to the previous level of care. No one would discuss the fact that she needed more care and I was told she was back to how she was; well,*

*only me knew that she wasn't, because they didn't know how she was before … "*

<div align="right">Brenda, daughter of Helen</div>

Apparently inappropriate discharge plans seemed to diminish feelings of trust that family carers had for health care professionals. Evelyn described the process by which the decision was reached to discharge her aunt from hospital:

*"(Gloria) was sitting in a chair, the first time I'd seen her in a chair … the doctor came round. While we was there and he said to her "Stand up" well she eventually managed to get up with both her arms and he shoved a walker in front of her he said 'Now take me a few steps" she took one step and he said "Right she can go home Wednesday'."*

<div align="right">Evelyn, niece of Gloria</div>

For some family carers, a short-term outcome was the feeling of disappointment due to the lack of relationship with members of staff. When Eric was admitted to hospital, his daughter Tina commented:

*"It wasn't quite such a nice experience with dad, I must admit. There was no friendly banter between the staff, there was no, oh I don't know, I wouldn't say no communication, because you could have walked up to them and talk to them whatever if you wanted to I suppose, but you did feel as though you shouldn't be doing that, because they are busy, they've got a lot of patients to look after."*

<div align="right">Tina, daughter of Eric</div>

Where communication was better and relationships warmer, the short-term outcome for family carers appeared to be increased levels of satisfaction and trust on the part of the family carer. Brian appeared to have a great sense of trust in the nursing staff as a result of the quality of the relationship he had with them, even though the information they had to relay to him was not positive:

*"The staff nurse … was very good, always got time to talk to you and explain things at length and reassure you, although it was obvious with my mother, that we were sure it was terminal then, we thought she'd perhaps got a month or two at best."*

<div align="right">Brian, son of Hannah</div>

Bernice experienced feelings of satisfaction as a result of the quality of spontaneous communication and information giving from members of staff on the ward:

*"Well once she was in the new ward everything was lovely, because they would sort of walk up to you and say, 'Oh she's much better today', and*

*you wouldn't even have to ask... That was great, and all those things add up to make you feel better..."*

<div align="right">Bernice, daughter of April</div>

## Long-term outcomes

The more negative long-term family carer outcomes seemed to be anger (with individuals, teams and the system), discontent with inaccurate information resulting in formal complaints, guilt, feeling unprepared for future care needs and reaching a fixed opinion that the service was of a poor quality.

Feelings of anger seemed to be directed at both members of staff for the decisions that they made as well as at the NHS as a whole for inadequacies in the system. Kirsty expressed anger at the state of the sideward that was allocated to her mother:

*"The first time she went in … I questioned every time, why she was in a grotty, it was filthy, I took pictures on my phone; the room was dirty."*

<div align="right">Kirsty, granddaughter of Florence</div>

Jill was angry at a system where her mother was sent to a discharge lounge where members of staff did not know anything about her:

*"I went up to the thing and I said 'I've come to collect my mum.' 'She's over there.' I said 'Do you not have any handover? Are you not going to tell me what the doctor's...' 'We don't know anything.' Well at this point I just said 'This is ridiculous, my mother doesn't even know where she is, she thinks she's on a day trip to Skegness, and you have no handover whatsoever from the ward?'"*

<div align="right">Jill, daughter of Betty</div>

Bernice expressed a general anger at a hospital system that she believes fails to meet the needs of the people who are admitted into them:

*"It makes me feel angry that so much money is being poured into this hospital system and it doesn't work, it really doesn't work ...there is never a space for anyone to be able to breathe and come and say to you, this is what's happening, that's what's happening, we'll be back to you at this time. You don't know, you wait, you wait, and you wait..... But I'm getting to the point now where I don't feel I want to go along with it anymore, I want to express my views, I want to tell them that it isn't working, and I want to tell them what a complete and utter waste of time and money"*

<div align="right">Bernice, daughter of April</div>

Inadequate or inaccurate information seemed to be a cause of some long-term discontent on the part of family carers. Francesca felt she had wasted time considering care homes that were never an option for her aunt:

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*"… and it wasn't clear from liaison between us, the hospital and social services, that she did need dementia care and that was a must, so once we knew that we then started looking for a care home that had the right dementia care … if somebody had said it at the beginning we would have looked down the route, but the social worker came back with oh there's this home, this home … this one does dementia, this one doesn't, and by that you think well you don't need to tell me about the ones that don't because obviously with hindsight they weren't appropriate in any event.."*

Francesca, niece of Bettina

Where family carers were deeply dissatisfied with the treatment that either they or their relative received, the long-term outcome was a letter of complaint. Some family carers simply wanted recognition that the care provided was inadequate, while others hoped their complaints would subsequently improve the care given to other people. Erika and Kirsty explained what they hoped to achieve by complaining about the care their mother received:

*Erika:* *"A letter is not going to put what happened to mum right."*

*Kirsty:* *"And it's not about the money again, it's not, it's like…you know, we don't want a big pay-off to say, we'll sue you... We want closure, don't we? We want somebody to tell us… to turn round and say we did this wrong…"*

Erika, daughter and Kirsty, granddaughter of Florence

Where the discharge destination from hospital was a care home, the long-term outcome for the family carer was sometimes one of guilt. For Brian his mother's stay in hospital was the point at which he realised that he could no longer care for her at home:

*"I was there when the registrar was interviewing my mother once, or tending to my mother, and she asked my mother where she'd like to be. And mother said, 'Home,' and as she said it, her face lit up and she smiled from ear to ear, I've never seen anybody, the face change like that, and it, I just felt horribly guilty, that I couldn't, you know, I just couldn't agree to this."*

Brian, son of Hannah

In other situations, family carers felt that they had not been informed of symptoms to monitor for future occurrences of the physical problem. This meant that they were not well placed to seek intervention to avoid readmission to hospital being a necessity.

A final negative long-term outcome for family carers was that they appeared to reach a fixed view on one or more aspects of the service being of a poor quality.

Frank's wife reached the view that the staff on the ward seemed to focus on lots of activity without really delivering quality care:

*"He was just left on a bed rotting away absolutely rotting away... the sisters they tell you things, but you never saw the same one twice, staff nurses just doing their jobs and machines and bloods or what do you call them, injections and things but then where is the care of getting someone motivated? There isn't any."*

Muriel, wife of Frank

By contrast, other family carers experienced positive long-term outcomes with some reaching a fairly fixed view that the quality of care was quite good, even where they had specific criticisms. Francesca was appreciative of the efforts the members of staff took to ensure her aunt had something to eat:

*"They were very kind in that ... she wasn't eating at mealtimes when I went, she'd say "I'm going to have my dinner now", and I'd say, "Oh dinner's gone, it's six o'clock", you know, and she said, "No, no, I haven't had anything", and then the nurse came along with a sandwich for her, she said she hadn't been eating her meals, but then she's demanding bread and butter at all times, and they'd brought her a cheese sandwich, so they were trying to feed her out of time, which clearly has to be done if she's not eating her meal, but it adds to their burden, I appreciate that. So they were very good with that."*

Francesca, niece of Bettina

Similarly, Lucy was happy with the attention members of staff paid to her mother's needs:

*"Well everything was very good really. Even down to if you needed a spare nightie or anything; they were there with things weren't they. I can't really think of anything to fault them with..."*

Lucy, daughter of Freda

Another positive long-term outcome for some family carers was that, after their relative's hospitalisation, they felt supported by members of staff when making decisions. Bernice was concerned about persuading her mother of the need to move into a home but felt well supported by the hospital team in this:

*Bernice: "You need that little clique of people there that agree with you, and they're in authority and they can say to her, well in my opinion [April] you cannot look after yourself, you need help, and if you're falling all the time one of these times you're going to come in and you're going to be seriously ill, because you are going to do some real bad damage to yourself. And this was the way it was put to her."*

*Int: "And how did she take it?"*

*Bernice: "She started to agree with us, you know, but had it have been me, because I'm her daughter, she would have been the opposite and said, you're not getting me in a place like that."*

Bernice, daughter of April

### 5.5.4 Co-patient outcomes

The immediate outcomes for co-patients were repeated so frequently that they became short-term outcomes. However, there was little evidence that they were long-term issues. The main outcomes seemed to be feelings of agitation, experiences of unnecessary pain and exhaustion. Each of these appeared to relate to the limited capacity of the system to respond appropriately to the needs of confused older patients therefore, causing disruption to co-patients. The main source of agitation for co-patients seemed to be the experience of having someone with confusion in the same bed area when they themselves felt unwell and vulnerable. By the end of the hospital stay, the main outcome for the co-patients in this study appeared to be feelings of exhaustion:

*"The only thing that was really annoying is you came out tired, more tired than when you went in, you know. So I think there's definitely an aspect there that they shouldn't put mental people with... (people who do not have dementia)"*

Mike, co-patient

### 5.5.5 Staff Outcomes

Due to the methods used to gather data, relatively few staff outcomes were identified in this part of the overall study. In the short-term members of staff were freed to do other things when family carers got involved in delivering care. However, working practices sometimes created unnecessary extra work and stress and, ultimately having the potential to cause burnout.

On occasions there appeared to be reluctance on the part of ward staff to allow family carers to get involved in care and it was perceived that this made their jobs more difficult. Sally expressed her frustration about this:

*"It would have only taken no more than five minute to get her all dressed. I've dressed her for so long now, I do it, actually less than five minutes. … I think they made their jobs harder, and by making their jobs harder it made it harder on my mother, and it needn't have been that way, it could*

*have been a lot easier on the nurses, a lot less time consuming for them, and easier on my mother and on me."*

<div align="right">Sally, daughter of Victoria</div>

Similarly, Diane found that the failure to provide assistance on a timely basis resulted in unnecessary additional work for members of staff:

*"There were one or two nasty misses [toileting] and all this sort of thing, but even when they used to shout I want to go to the loo nobody actually came, you had to wait, well some of them by that time had done it, and then you needed another bed changed."*

<div align="right">Diane, wife of Sidney</div>

Ultimately, the major long-term outcome for some members of staff was increased stress and a higher risk of burnout. This was illustrated in a conversation during a ward observation:

*It's chaotic at times. I often feel out of control. When the relatives are in your face too... I go home and have to wind down before I can face my kids. And that saddens me...I do get fed up repeating myself and do just dart away. It's how I cope. But it probably isn't right*

<div align="right">Field notes, conversation with ward staff during observation</div>

This tended to be compounded by what staff felt to be unobtainable expectations from the organisation with regard to the quality of care that should be delivered. This was illustrated in a snatched conversation during a ward observation:

*We can't give 1:1. And I get really upset when I see a fall. I feel it's my fault. Even if I've done everything else, I feel it's my fault. And of course it isn't as I can't be everywhere. But we know we are judged on the falls not on how well we feed somebody or keep them busy.*

<div align="right">Field notes, conversation with ward staff during observation</div>

### 5.5.6 Summary of discussion of outcomes resulting from the interaction of the core problem and core process

Overall, outcomes were apparent for all four groups, although the most evidence was for family caregiver and patient outcomes. Outcomes fell into three broad categories: immediate responses, short-term outcomes and long-term outcomes.  While co-patients appeared to experience only immediate responses and short-term outcomes, all other parties seemed to experience all categories of outcomes.

By their definition, immediate responses were influenced by the event which directly preceded the response and there was no discernable pattern to this within the data. There were more negative than positive short-term outcomes, although for co-patients these tended to be exclusively negative. However, the majority of the long-term outcomes that appear as a result of the interaction of the core problem and core process were negative for patients, family carers and members of staff.

## 5.6      Chapter summary

This chapter reported on the findings of the ethnographic grounded theory study of the experience of hospitalisation from the perspectives of the confused older patient, the family carer and the co-patients who share the ward area. The observations and interviews revealed a core problem of "disruption from normal routine" which affected all parties and the hospital staff who formed a fourth group in the analysis. The actions of these four parties were interpreted as "gaining or giving a sense of control to cope with disruption". Accounts of how representatives from each group maintained a sense of control have been presented as the core process. Finally, the outcomes of the interaction between the core problem and the core process revealing a range of consequences for confused patients and the other key players.

# 6 DISCUSSION

## 6.1        Summary of findings

This project comprised two linked studies. One examined staff and organisational attitudes to dealing with confused older patients, their opinions and concerns about their training and their suggestions for positive changes. The other examined the effect of hospitalisation on confused older people, their carers, co-patients and staff to identity potential improvements in this process.

Staff perceived confused older patients as characterised by challenging behaviours, which they did not understand, did not know how to deal with, and which affected their ability to provide good care. In the authors' opinion, it is rare to see such a large proportion of any professional group feel so poorly prepared to take on the task in hand. Staff who reported feeling confident in their own competence to deal with confused older patients were invariably those who by chance had relevant experience outside of hospital settings, either within their own families or in care homes. Senior medical staff reported their lack of confidence in training juniors, and considered the curriculum to be out of balance with the patient mix seen by most doctors in their future working lives. Senior nurses reported new entrants to be unprepared for the level of personal care required, and experienced difficulties recruiting staff to work with this patient group. Most staff had no idea on entering their various professions that this group of patients would represent such a significant part of their workload.

The reasons why all staff groups were and felt so ill prepared to look after older people with cognitive impairment are likely to be complex. In the Introduction, we speculated the undergraduate professional education may be based on models that focus on pathologies or tasks and that these may not prepare staff for dealing practically with patients. Our staff respondents mainly identified lack of training an education on job induction and a lack of in-service training. Doctors and nurses felt some sort of training should be mandatory. Mandatory training may be necessary given that the training needs of healthcare assistants were overlooked, ward managers' expressed difficulty in releasing nursing staff for in-service training and senior doctors felt inadequately skilled to train their juniors. Other suggestions from doctors included the routine inclusion of a period of training in geriatric medicine in all training programmes – an idea that could extend to the training of all professional groups.

Many factors were perceived to combine and make these patients a more demanding group in terms of staff time than other (non-confused) patients on the acute ward: communication, initial assessment, personal care, aggressive behaviours, wandering, inability to co-operate with rehabilitation activities within the usual timescales, and liaising with relatives. The knock-on effects for co-patients, many of whom would often be more acutely ill than confused older patients, concerned staff and gave rise to tension. Dealing with angry co-patients and their families was a significant source of staff stress. Opinions were offered about the unrealistic expectations of the general public as to what hospital staff could feasibly provide given their resources. It was thought that the demands of caring for confused patients were not recognised by hospital-wide systems and targets. When asked which type of staff would be most helpful for them in providing improved care for confused older people in hospitals, most participants suggested healthcare assistants (auxiliary nurses) on the ward and better access to mental health specialists within the hospital, whether it be from a 'flying squad' or via a single point central referral system. The lack of resources for confused older patients on the ward, such as day rooms and activities, were thought to have implications for their unhappiness, decreasing physical and mental capacity and confidence, and length of stay in hospital. Staff found the design of their physical work environment with respect to the safety of confused patients difficult to manage. Keeping an eye on wandering patients, trying to prevent them from injuring themselves or disturbing others, was demanding.

There was a strong feeling that some of these patients did not need to be in hospital. Their presence was attributed to inappropriate referral by General Practitioners or locums, and to families who simply could no longer cope without support and presented to the emergency department. Furthermore, once in hospital, staff felt frustrated about their inability to move patients on to a setting more suitable than an acute hospital ward. Discharge coordinators were highly valued in terms of saving nurses and doctor's time. The tensions of nursing this time-intensive group of patients, particularly once they no longer needed in-hospital medical treatment and were perceived to be simply waiting for suitable care package before discharge, were strongly felt. Many senior doctors reported that this was an inappropriate setting, where frail patients acquired infections and secondary medical problems that further lengthened their stay, and that many patients entered an unnecessarily fast downward spiral from which it was difficult to recover. Avoiding admissions and improving liaison with social services were thought to be an important matter for future exploration, as was improving communication between the various professional groups involved in their care.

The challenges that staff experienced caring for confused older patients, and the perceived lack of resources to provide a standard of care they were happy with had implications for their own job satisfaction and well-being. They often felt powerless to provide adequate help to patients, and were

very concerned about the quality of patient care and dignity. Whilst staff attitudes were not wholly positive, most were sympathetic, and the overwhelming response was frustration at not feeling enabled by training, facilities or systems to provide better care. The small wins they could experience in being able to improve the quality of life for this vulnerable patient group and their relatives gave them a great sense of satisfaction. However, most felt the NHS had not woken up to the size of the problem, that confused elderly patients were being treated like 'leftovers in the system', and that the resulting challenges for the staff who care for them were ignored.

The findings of the interviews and observations of confused patients, their carers and co-patients were explained as a *core problem* , being the disruption to patients', carers', staffs' and co-patients' routines and expectations,  and a *core process*, being attempts to cope with these disruptions by aiming to achieve or give control. The consequence of these disruptions and responses often led to immediate, short, and long term consequences. Some of these consequences were adverse, such as serious iatrogenic conditions. These findings help to explain how health care processes lead to poor outcomes and hence how these poor outcomes might be prevented.

These studies are larger than any previously conducted. While both the current studies were run in parallel, they proceeded entirely independently of each other, conducted by researchers from different disciplines without sharing of data processes or methods. The coherence of the results from both studies gives added weight to the findings. A potential limitation is that the findings here, being those from a single institution, may not be representative of all people and all hospitals across the board. For example, we do not know if staff would have reported being more confident and supported in hospitals with a liaison psychiatry service. However, we sampled a wide range of wards typically found in general hospitals. The findings fit so consistently with those of the literature reviews that it would seem that these deficiencies are not unique to this institution. Together, the findings presented here raise systemic issues for policy and practice related to the hospital care of cognitively impaired older people in general hospitals. Changes are necessary to recognise that care of older people with mental health problems is core business of general hospitals. This represents nothing less than a culture shift. Failure to do so will perpetuate poor outcomes and negative experiences of hospital care for patients and carers alike, delivered by a poorly skilled, de-motivated workforce.

## 6.2 Recommendations

Dementia and delirium or at least the presence of cognitive impairment should be recognised, early, and by all staff groups. Clear documentation of mental health problems in medical notes is needed. This could easily be achieved by the routine use of simple screening tests on all older people admitted to hospital, such as the Abbreviated Mental Test score (96) and the Confusion Assessment Method (97).

Identifying which aspects of current care processes and pathways fail to accommodate the high incidence of cognitive impairment in the population accessing secondary care will improve care delivery. Some aspects of service delivery even compound confusion. Unnecessary admissions to hospital should be avoided in any case, but they are particularly detrimental to the wellbeing of people with cognitive impairment. Once admitted, hospital processes can generate multiple disruptions. Frequent moves such as the practice of "sleeping out" a patient whose acute medical intervention has finished to a less intensive ward in the hospital should be avoided; otherwise this will further disrupt the attempts for all players to gain control.

All staff groups regularly caring for older patients, irrespective of their specialty, status and seniority, should be trained to deal with this group of patients and their relatives, and the effects they have on co-patients. *A guide to training the social care and health workforce* has been developed by Skills for Care (1) and elaborates these key training points. They have detailed 8 core principles inherent to high quality care for older adults with dementia:

1. Know the early signs of dementia

2. Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.

3. Communicate sensitively to support meaningful interaction

4. Promote independence and encourage activity

5. Recognise signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience

6. Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice

7. Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia

8. Work as part of a multi-agency team to support the person with dementia

Identifying deficiencies in the current system and addressing staff training in the context of these principles will enable organisations to improve care delivery. Workplace-based training is likely to be the most feasible and acceptable, not least to allow staff to reflect on the degree to which they are disrupted and the degree to which they respond by attempting to exert control. Prevention and management of aggressive behaviour is a core feature of training for staff in the mental health sector. It is now clear that this training needs to be replicated for all staff in general hospital settings.

New practices should arise from such training, and these might include routine discussions with carers of patients identified as having cognitive impairment , to ascertain the information necessary to understand the patient, to allay the fears or worries of the carer, and to prepare for the patient's eventual discharge. This information should be recorded so that even though these patients may not be able to explain their personal preferences and specific needs (as patients without cognitive impairment would do) staff are able to take then into account when planning and delivering care. Although multidisciplinary meetings are not new, and indeed are accepted elements of good care, improving communication between doctors, nurses and other professionals involved in patient care and discharge as would be achieved by such meetings would appear to be valuable. Use of the information so received and shared may allow staff to reduce the occurrence of challenging behaviour and other problems, and may also help reduce excessive lengths of stay, such as when such early discussion identify a pressing need to arrange for an early discharge to avoid the collapse of a community care package.

More explicit support for carers and encouragement or at least overt permission for them to contribute to patient care could help to improve patients' safety and nutrition, relieve patient boredom, ameliorate co-patient concerns and help to reduce demands upon nursing staff. The timing and duration of visiting times should be re-considered. Hospitality and accommodation for carers, as would be provided for parents of child patients, should be available.

Providing care for older people with cognitive impairment is complex, difficult, time consuming and emotionally burdensome. Staff need to be trained appropriately and wards resourced accordingly.

Since older adults with mental health problems are cared for on most wards in most departments of general hospitals, provision of information for co-patients and visitors may promote understanding and empathy. Being able to provide better care will have benefits all round – to the patient, to their carer, the co-patients, and to the staff themselves. Nevertheless, staff support mechanisms, as would be routine in mental health settings, should

be established to help prevent staff burnout and long term stress from untoward events such as episodes of violence.

Hospital environments need to be designed and renovated with the needs of confused older patients and their carers in mind. Development of a "good environment" checklist could go some way to addressing this issue. In the physical environment, examples might include improved signage and visual contrast, and more explicit removal of hazards such as putting boxes to store used hypodermic syringes in locked areas. Activity areas could be protected and made suitable for use by patients and their carers. There is a need for more volunteers and activities coordinators to facilitate psychosocial interventions.

Hospital processes and organisation also need to be changed. Frequent moves of older people with mental health problems should be avoided as they further disrupt the attempts for all players to gain control. Ward nursing staff establishments need to be calculated taking the emotional and psychological needs of the patients into account. The more patients with mental health problems there are on a ward the more time and effort will be required to deal with them. Failure to recognise this represents failure of the organisation to respond to a core need.

*The National Dementia Strategy* (18) in England has called for the commissioning of liaison old age psychiatry services. These could potentially provide resources and leadership for ongoing workplace-based education and facilitate changes in the structure and process of acute hospitals. To do so, such services would have to do more than merely provide a rapid and skilled response to referrals of individual patients. General hospitals could develop a specialist ward for older people with cognitive impairment which could not only provide care for the most difficult management problems, but serve as a resource for workplace-based training, and a hub in which an expert workforce could be developed (98, 99) .

Since care of older people with cognitive impairment is core business, provision of a liaison service or a specialist unit alone should not be seen as a sufficient response by a general hospital. Education and changes to practice are needed wherever patients with cognitive impairment are managed, including surgical and specialist medical wards. Whether or not liaison psychiatry services for acute hospitals, specialist units, or both are commissioned, sustained high level commitment from health service policy makers for the care of older people with cognitive impairment is needed and investment is required.

Regarding further research into the care of people with delirium and dementia in hospital, the need now is to evaluate interventions rather than re-iterate the problems. Examples of services raised by this research as worthy of development and evaluation include admission avoidance and early discharge schemes for people with cognitive impairment, liaison old age psychiatry services, and specialist units for delirium and dementia.

Interventions to improve staff competence and confidence in their competence in the management of people with cognitive impairment should also be developed and evaluated. Interventions to deal safely with behaviours such as wandering or sleeplessness should be investigated. Innovations in the design of the physical environment and its effect on behavioural issues such as agitation should be explored and evaluated. Interventions involving systematic engagement of family carers to improve patient and carer outcomes are warranted. Evaluations of any of the above should take a system-wide perspective and consider patient, carer, co-patient and staff experiences, their safety, and the effectiveness of interventions in immediate, short term and long term outcomes.

Concerted efforts are required to disrupt the vicious spiral of poor care and replace it with a virtuous cycle of high quality patient-centred care, with well-trained staff, good communication, an adaptive environment and a proactive organisation at its core.

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# References

1.      Skills for Care & Skills for Health. Common Core Principles for Supporting People with Dementia- A guide to training the social care and health workforce2011: Available from: http://www.skillsforcare.org.uk/developing_skills/dementia/supporting_people_with_dementia.aspx.

2.      Royal College of Psychiatrists. Who Cares, Wins2005: Available from: http://www.rcpsych.ac.uk/college/faculty/oap/index.htm.

3.      BBC. Available from: http://www.bbc.co.uk/news/uk-scotland-13551728.

4.      Alzheimer's Society. Counting the cost. Caring for people with dementia on hospital wards2009: Available from: http://alzheimers.org.uk/countingthecost.

5.      Roper N., Logan W., Tierney A.J. The Roper-Logan-Tierney Model of Nursing: Based on Activities of Living. Edinburgh: Elsevier Health Sciences; 2000.

6.      Gordon AL, Blundell AG, Gladman JRF, Masud T. Are we teaching our students what they need to know about ageing? Results from the UK National Survey of Undergraduate Teaching in Ageing and Geriatric Medicine. Age & Ageing. 2010 May;39(3):385-8.

7.      Royal College of Psychiatrists. National Audit of Dementia (Care in General Hospitals)2010: Available from: http://www.rcpsych.ac.uk/pdf/The%20Interim%20Report.pdf.

8.      Gladman JRF, Jurgens F, Harwood R, Goldberg S, Logan P. Better mental health in general hospitals. Medical Crises in Older People discussion paper series [serial on the Internet]. 2010: Available from: http://www.nottingham.ac.uk/mcop/documents/papers/issue3-mcop-issn2044-4230.pdf.

9.      Department of Health UK. National Services Framework for older People2001: Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/publications/publicationspolicyandguidance/DH_4003066.

10.     Holmes J, Bentley K, Cameron I. Between Two Stools: Psychiatric services for older people in hospital2002: Available from: http://www.leeds.ac.uk/lpop/documents/betweentwostools.pdf.

11.     Care Services Improvement Partnership. Everybody's Business. Integrated mental health services for older adults. A service development guide.2005: Available from: http://www.mentalhealthequalities.org.uk/silo/files/six-key-messages.pdf.

12.     Royal College of Psychiatrists. Raising the Standard. Specialist services for older people with mental health illness.2006: Available from: http://www.rcpsych.ac.uk/PDF/RaisingtheStandardOAPwebsite.pdf.

13.     Philp I. A new ambition for old age: next steps in implementing the National Service Framework for Older People.: Department of Health; 2006. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance?DH_4133941.

14.     NICE Guideline. Dementia: Supporting people with dementia and their carers in health and social care. Available from: http://www.nice.org.uk/CG42.

15.     Academy of Medical Royal Colleges. Managing urgent mental health needs in the acute trust2008: Available from: http://aomrc.org.uk/aomrc/admin/reports/docs/MHdoc.pdf.

16.     Healthcare Commission. Equality in Later Life. A national study of older people's mental health services2009: Available from: http://www.cqc.org.uk/db/documents/Equality_in_later_life.pdf.

17.     Academy of Medical Royal Colleges. No Health without Mental Health2009: Available from: http://www.aomrc.org.uk/aomrc/admin/reports/docs/NMMH_EMAIL.pdf.

18.     Department of Health. Living well with dementia2009: Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_103137.

19.     Department of Health. The Essence of Care: Patient focused benchmarking fro healthcare practitioners. Gateway reference 46562001: Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005475.

20.     NHS Institute for Innovation and Improvement. The Productive Ward-releasing time to care: Available from: http://www.institute.nhs.uk/quality_and_value/productivity_series/productive_ward.htm.

21.     Mental Capacity Act 2005. Available from: http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1.

22.     Care Quality Commission. Available from: http://www.cqc.org.uk/.

23.     Care Quality Commission. Reports into dignity and nutrition for older people2011: Available from: http://www.cqc.org.uk/newsandevents/newsstories.cfm?widCall1=customWidgets.content_view_1&cit_id=37384.

24.     The Local Authority (Overview and Scrutiny Committees Health Scrutiny Fucntions) Regulations 2002. Statutory Instrument 2002 No. 3048: Available from: http://www.opsi.gov.uk/si/si2002/20023048.htm.

25.     Adams T. Kitwood's approach to dementia and dementia care: a critical but appreciative review. Journal of Advanced Nursing. [Review]. 1996 May;23(5):948-53.

26.     Adams T, Gardiner P. Communication and interaction within dementia care triads. Dementia. 2005 June 1, 2005;4(2):185-205.

---

27. Borbasi S, Jones J, Lockwood C, Emden C. Health professionals' perspectives of providing care to people with dementia in the acute setting: Toward better practice. Geriatric Nursing. 2006 Sep-Oct;27(5):300-8.

28. Eriksson C, Saveman B-I. Nurses' experiences of abusive/non-abusive caring for demented patients in acute care settings. Scandinavian Journal of Caring Sciences. 2002 Mar;16(1):79-85.

29. Leung D, Todd J. Dementia care in the acute district general hospital. Clinical Medicine. 2010 Jun;10(3):220-2.

30. Nolan L. Caring for people with dementia in the acute setting: a study of nurses' views. British Journal of Nursing. 2007 Apr 12-25;16(7):419-22.

31. Philp I, Mutch WJ, Ballinger BR, Boyd L. A comparison of care in private nursing homes, geriatric and psychogeriatric hospitals. International Journal of Geriatric Psychiatry. 1991;6(4):253-8.

32. Cowdell F. Care of older people with dementia in an acute hospital setting. Nursing Standard. 2010 Feb 10-16;24(23):42-8.

33. Andersson EM, Hallberg IR, Edberg A-K. Nurses' experiences of the encounter with elderly patients in acute confusional state in orthopaedic care. International Journal of Nursing Studies. 2003 May;40(4):437-48.

34. Benjamin LC, Spector J. The relationship of staff, resident and environmental characteristics to stress experienced by staff caring for the dementing. International Journal of Geriatric Psychiatry. 1990;5(1):25-31.

35. Doherty D, Collier E. Caring for people with dementia in non-specialist settings. Nursing Older People. [Review]. 2009 Jul;21(6):28-31.

36. Cunningham C, Archibald C. Supporting people with dementia in acute hospital settings. Nursing Standard. [Review]. 2006 Jul 5-11;20(43):51-5.

37. Pulsford D, Hope K, Thompson R. Higher education provision for professionals working with people with dementia: a scoping exercise. Nurse Education Today. 2007 Jan;27(1):5-13.

38. Dewing J. Care for older people with a dementia in acute hospital settings. Nursing Older People. 2001 May;13(3):18-20.

39. Atkin K, Holmes J, Martin C. Provision of care for older people with co-morbid mental illness in general hospitals: general nurses' perceptions of their training needs. International Journal of Geriatric Psychiatry. 2005 Nov;20(11):1081-3.

40. Hallberg IR, Norberg A. Strain among nurses and their emotional reactions during 1 year of systematic clinical supervision combined with the implementation of individualized care in dementia nursing. Journal of Advanced Nursing. 1993 Dec;18(12):1860-75.

41. Berg A, Hansson UW, Hallberg IR. Nurses' creativity, tedium and burnout during 1 year of clinical supervision and implementation of individually planned nursing care: comparisons between a ward for severely demented patients and a similar control ward. Journal of Advanced Nursing. 1994 Oct;20(4):742-9.

42.     Duquette A, Kerouac S, Sandhu BK, Ducharme F, Saulnier P. Psychosocial determinants of burnout in geriatric nursing. International Journal of Nursing Studies. 1995 Oct;32(5):443-56.

43.     Gilloran A, Robertson A, McGlew T, McKee K. Improving Work Satisfaction amongst Nursing Staff and Quality of Care for Elderly Patients with Dementia: Some Policy Implications. Ageing & Society. 1995;15(03):375-91.

44.     Dinshaw C. Surveying nursing practice on wards for older people with mental health needs. Nursing Older People. 2006 Nov;18(10):25-31.

45.     Cocco E, Gatti M, de Mendonca Lima CA, Camus V. A comparative study of stress and burnout among staff caregivers in nursing homes and acute geriatric wards. International Journal of Geriatric Psychiatry. 2003 Jan;18(1):78-85.

46.     Schneider J, Scales K, Bailey S, Lloyd J. Challenging care: the role and experience of healthcare assistants in dementia wards2010: Available from: http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1819-222.

47.     Novak M, Chappell NL. Nursing assistant burnout and the cognitively impaired elderly. International Journal of Aging & Human Development. [Research Support, Non-U.S. Gov't]. 1994;39(2):105-20.

48.     Proctor N, Stratton-Powell H, Tarrier N, Burns A. The impact of training and support on stressamong care staff in nursing and residential homesfor the elderly. Journal of Mental Health. 1998;7(1):59-70.

49.     Morgan DG, Stewart NJ, D'Arcy C, Forbes D, Lawson J. Work stress and physical assault of nursing aides in rural nursing homes with and without dementia special care units. Journal of Psychiatric and Mental Health Nursing. 2005;12(3):347-58.

50.     Pekkarinen L, Sinervo T, Elovainio M, Noro A, Finne-Soveri H, Leskinen E. Resident care needs and work stressors in special care units versus non-specialized long-term care units. Research in Nursing & Health. 2006;29(5):465-76.

51.     Alfredson BB, Annerstedt L. Staff attitudes and job satisfaction in the care of demented elderly people: group living compared with long-term care institutions. Journal of Advanced Nursing. 1994 Nov;20(5):964-74.

52.     Grant LAP, Potthoff SJP, Olson DMP. Staffing and Administrative Issues in Special Care Units. Alzheimer's Care Quarterly Summer. 2001;2(3):27.

53.     Duffy B, Oyebode JR, Allen J. Burnout among care staff for older adults with dementia. Dementia. 2009 November 1, 2009;8(4):515-41.

54.     Zimmerman S, Williams CS, Reed PS, Boustani M, Preisser JS, Heck E, et al. Attitudes, stress, and satisfaction of staff who care for residents with dementia. Gerontologist. 2005 Oct;45 Spec No 1(1):96-105.

55.     Baldelli MV, Fabbo A, Costopulos C, Carbone G, Gatti R, Zucchl P. Is it possible to reduce job burnout of the health care staff working with demented patients? Archives of Gerontology & Geriatrics - Supplement. 2004(9):51-6.

56.     Brodaty H, Draper B, Low L-F. Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. Journal of Advanced Nursing. 2003 Dec;44(6):583-90.

57.     Elovainio M, Sinervo T. Psychosocial stressors at work, psychological stress and musculoskeletal symptoms in the care for the elderly. Work & Stress. 1997 1997/10/01;11(4):351-61.

58.     Hughes J, Bagley H, Reilly S, Burns A, Challis D. Care staff working with people with dementia. Dementia. 2008 May 1, 2008;7(2):227-38.

59.     Kuremyr D, Kihlgren M, Norberg A, Astrom S, Karlsson I. Emotional experiences, empathy and burnout among staff caring for demented patients at a collective living unit and a nursing home. Journal of Advanced Nursing. 1994 Apr;19(4):670-9.

60.     Palmer AC, Withee BM. Dementia care: effects of behavioral intervention training on staff perceptions of their work in veterans' nursing home. Geriatric Nursing. 1996 May-Jun;17(3):137-40.

61.     Rodney V. Nurse stress associated with aggression in people with dementia: its relationship to hardiness, cognitive appraisal and coping. Journal of Advanced Nursing. 2000 Jan;31(1):172-80.

62.     van Beek APA, Gerritsen DL. The relationship between organizational culture of nursing staff and quality of care for residents with dementia: questionnaire surveys and systematic observations in nursing homes. International Journal of Nursing Studies. 2010 Oct;47(10):1274-82.

63.     Teri L, McKenzie GL, LaFazia D, Farran CJ, Beck C, Huda P, et al. Improving Dementia Care in Assisted Living Residences: Addressing Staff Reactions to Training. Geriatric nursing (New York, NY). 2009;30(3):153-63.

64.     Sandberg O, Gustafson Y, Brannstrom B, Bucht G. Prevalence of dementia, delirium and psychiatric symptoms in various care settings for the elderly. Scandinavian Journal of Social Medicine. 1998 Mar;26(1):56-62.

65.     Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339:b2535.

66.     Tolson D, Smith M, Knight P. An investigation of the components of best nursing practice in the care of acutely ill hospitalized older patients with coincidental dementia: a multi-method design. Journal of Advanced Nursing. [v't]. 1999 Nov;30(5):1127-36.

67.     Norman R. Acute nursing care for people with dementia, what happens when a person with dementia is admitted to hospital? Bristol: UWE; 2003.

68.     Norman R. Observations of the experiences of people with dementia on general hospital wards. Journal of Research in Nursing. 2006 September 1, 2006;11(5):453-65.

69.     Formiga F, Olmedo C, Lopez-Soto A, Navarro M, Culla A, Pujol R. Dying in hospital of terminal heart failure or severe dementia: the circumstances

associated with death and the opinions of caregivers. Palliative Medicine. 2007 Jan;21(1):35-40.

70.     Douglas-Dunbar M, Gardiner P. Support for carers of people with dementia during hospital admission. Nursing Older People. 2007 Oct;19(8):27-30.

71.     Naylor MD, Hirschman KB, Bowles KH, Bixby MB, Konick-McMahan J, Stephens C. Care coordination for cognitively impaired older adults and their caregivers. Home Health Care Services Quarterly. 2007;26(4):57-78.

72.     Hill CE, Knox S, Thompson BJ, Williams EN, Hess SA, Ladany N. Consensual Qualitative Research: An Update. Journal of Counseling Psychology. 2005;52(2):196-205.

73.     Hill CE, Thompson BJ, Williams EN. A Guide to Conducting Consensual Qualitative Research. The Counseling Psychologist. 1997 October 1, 1997;25(4):517-72.

74.     Office for National Statistics. Household Questionnaire England. London2011.

75.     QSR International Pty Ltd. QSR NVivo Version 8.0.340.0 SP4. 2008.

76.     Hellstrom I, Nolan M, Nordenfelt L, Lundh U. Ethical and methodological issues in interviewing persons with dementia. Nursing Ethics. [Review]. 2007 Sep;14(5):608-19.

77.     Tedlock B. Ethnography and ethnographic representation. In: Denzin N, Lincoln Y, editors. Handbook of Qualitative Research. Thousand Oaks, California: Sage Publications; 2000.

78.     Aggarwal N, Vass AA, Minardi HA, Ward R, Garfield C, Cybyk B. People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care. Journal of Psychiatric and Mental Health Nursing. 2003;10(2):187-97.

79.     Riessman K. Narrative Analysis: Qualitative Research Methods Series. Newbury Park, California: Sage Publications; 1993.

80.     Nygard L. How can we get access to the experiences of people with dementia? Suggestions and reflections. Scandinavian Journal of Occupational Therapy. 2006 Jun;13(2):101-12.

81.     Moore TF, Hollett J. Giving voice to persons living with dementia: the researcher's opportunities and challenges. Nursing Science Quarterly. 2003 Apr;16(2):163-7.

82.     Kitwood T. Dementia reconsidered: the person comes first. Maidenhead: Open University Press; 1997.

83.     Brooker D. What is person-centred care in dementia? Reviews in Clinical Gerontology. [Review]. 2003 Aug;13 (3):215-22.

84.     Brooker D. Person-centred Dementia Care. London and Philadelphia: Jessica Kingsley Publishers; 2007.

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85. Vidich A, Lyman S. Qualitative methods: their history in sociology and anthropology. In: Denzin N, Lincoln Y, editors. Handbook of Qualitative Research. Thousand Oaks, California: Sage Publications; 2000.

86. Charmaz K. Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis. Los Angeles: Sage; 2006.

87. Medical Crises in Older People: Available from: http://www.nottingham.ac.uk/mcop/about.aspx.

88. Goldberg S, Harwood R, Gladman J, Bradshaw L, Whittamore K, Jones R. The prevalence of mental health problems amongst older adults admitted as an emergency to a general hospital. Age Ageing. 2012;41:80-86.

.

89. Rodwell MK. Social Work Constructivist Research. New York: Garland Publishing; 1998.

90. Glaser BG, Strauss A. The Discovery of Grounded Theory: Strategies for qualitative Research. Chicago: Aldine Press; 1967.

91. Glaser BG. Theroetical Sensitivity. Mill Valley, California: The Sociology Press; 1978.

92. McCutcheon M. Roget's Super Thesaurus. Fourth ed. Cincinnati: Writer's Digest Books; 2010.

93. de Boer ME, Hertogh CMPM, Droes R-M, Riphagen II, Jonker C, Eefsting JA. Suffering from dementia - the patient's perspective: a review of the literature. International Psychogeriatrics. [Review]. 2007 Dec;19(6):1021-39.

94. Lazarus RS, Folkman S. Stress, Appraisal and Coping. New York: Springer Publishing; 1984.

95. Collins. Collins English Dictionary. Millenium Edition. Glasgow: Harper Collins Publishers; 1999.

96. Hodkinson HM. Evaluation of a mental test score for assessment of mental impirment in the elderly. Age and Ageing. 1972 November 1, 1972;1(4):233-8.

97. Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying Confusion: The Confusion Assessment Method. Annals of Internal Medicine. 1990 December 15, 1990;113(12):941-8.

98. Harwood R, Porock D, King N, Edwards G, Hammond S, Howe L, et al. Development of a specialist medical mental health unit for older people in an acute general hospital. Medical Crises in Older People Discussion paper series [serial on the Internet]. 2010; (5): Available from: http://www.nottingham.ac.uk/mcop/documents/papers/issue5-mcop-issn2044-4230.pdf.

99. George J, Adamson J, Woodford H. Joint geriatric and psychiatric wards: a review of the literature. Age and Ageing. 2011 September 1, 2011;40(5):543-8.

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