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To promote the better health of older people through encouraging inter-disciplinary training, research and excellence in practice and services.

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A note from the editors

Welcome to the latest edition of the Journal of the Institute of Ageing and Health. This issue has seen us expand and develop our peer review process to ensure we reflect the ethos of the Institute and uphold rigour. The journal is not viable without people's contributions and we would encourage our readers to spread the word. Do you know anyone involved with working with older people who has a project or has presented on the work they are doing? Encourage them to write about it. Without these contributors we would not be able to share research, scholarly work and discussion aimed at improving the experience of ageing and health in the West Midlands.

We would like to thank all the contributors to the journal. There are several papers considering dementia from a variety of perspectives. One article asks how well equipped nurses are in an acute care setting to care for people living with dementia. The following article considers best practice around pain assessment with people living with advanced dementia. Both of these papers link neatly into the paper which asks what the perceptions of people living with dementia and their carers and the quality of the care they receive.

Following on from the joint IAH and RCN event considering the multiple perspectives of the use of surveillance cameras to monitor care: there is a literature review within the journal on the ethics of their use. We have included an interesting article on the early detection of cancer in men and whether it is possible to identify if they need more support in coping with and coming to terms with their diagnosis.

The Institute has been busy organising various educative events over the last year and into this year. Included in the journal is an overview of the learning from the workshops on sensory stimulation activities and their use with older adults. For those who attended; they were a fascinating and inspiring group of workshops which show cased best practice in a variety of settings.

We are hosting an event on the 31st March 2017 on frailty. The event is running twice due to high demand with morning and afternoon sessions available. We are delighted to have Dr. Dawn Moody, a GP from Derbyshire with a specialty interest in frailty and person-centred care along with Anna Lynall, an expert in self-care who is currently undertaking a PhD.

At the back of the journal are guidelines on how to submit your contribution so please join us and keep sending in any research or scholarly articles to continue to promote a network of shared expertise and interest around ageing and health. We would also encourage you to read our blogs, visit our website at: http://iah-wmids.org.uk/index.php/blog.

Dr Ruth Pearce and Sue Lillyman

Contributions for publication must be typewritten with double space. Contributors should check personally the accuracy of any references which are to be quoted by name and date. Photographs (black and white) should be written on an accompanying sheet of paper and not on the back of photographs. Photographs, diagrams and drawings submitted for publication should where possible be no smaller than 3 1/4" x 4 1/4". The Publications Committee retains the right to edit letters and does not necessarily share opinions expressed by contributors.

Learning from the workshops on sensory stimulation activities and their use with older adults

Authors: Alison Whyte, (Independent editor and writer), Dr Ruth Pearce (member of the executive Board for IAH)

Acknowledgements: Eleanor Bradley, Marcus Fellows, Michelle Meehan, Julia Lowe, Dr Claire Garabedian

Introduction

The Institute of Ageing and Health (West Midlands) (IAH) Research and Education Committee decided to organise a series of workshops on sensory stimulation activities and their use with older adults.

The workshops were first suggested by Marcus Fellows, ex-Chair of IAH and Broadening Choices for Older People (BCOP). Marcus has been instrumental in developing and introducing sensory stimulation activities into BCOP homes, initially without support from Birmingham City Council or other funding bodies. He claimed he knew they worked but he couldn't articulate how or why. This prompted the committee to consider whether there was any evidence to suggest that sensory stimulation activities have any impact and if they improve the quality of life of older adults.

The first workshop set the scene in terms of considering evidence and whether the evidence on sensory activities was considered valid and reliable. Professor Eleanor Bradley, an expert researcher, gave a talk about evidence based practice and its value. Marcus Fellows then spoke of his work at BCOP and a copy of the IAH journal Ageing and Health was distributed with an article by Pearce (2016) on Sensory stimulation activities: is there any evidence?

Workshop two continued the theme with Michelle Meehan, Lead Activity Co-ordinator and Julia Lowe, Environmental and Horticultural Co-ordinator at BCOP described the importance of creating a perfect environment for residents and individualising their care. This was followed by workshop three with Dr Claire Garabedian, Associate Researcher in the Creative Arts and Dementia from the Association for Dementia Studies within the University of Worcester explaining how music can enhance the lives of people living with dementia as well as their carers.

Below is a summary of the workshops and the key learning from each to enable recollections of the workshops and how they have developed our thinking on sensory stimulation activities.

Workshop 1

Dr Eleanor Bradley, Professor of Health Psychology at the University of Worcester began this workshop by asking what is evidence-based practice and why is it important?

One definition might be 'The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from *systematic* research' (Sackett et al 1996). She described the various types of evidence – systematic reviews, randomised control trials (RCTs), cohort studies, case-controlled studies, programme evaluations, opinion surveys, case studies and expert opinion and she provided a description of each.

Of these, RCTs are seen as the 'gold standard' in research design because they are considered more objective. In RCTs people are randomly allocated to receive (or not to receive) an intervention. This could be two different treatments or one treatment and a placebo.

However, even if high-quality research can provide the best evidence, it is not always available. Some topics are under researched, new therapies have not yet been tested, and there are person-centred approaches that do not lend themselves to scientific study. Furthermore, findings from RCTs have been criticised for producing results which do not necessarily transfer to 'real-world' environments.

She also suggested that even if research is considered gold standard, the wrong conclusion may be drawn from it. Also, some studies are funded by organisations or individuals with a possible vested interest.

The issue of RCTs raises important ethical questions. Although patients may gain from taking part, this is not the primary aim of the trial and despite the need to protect patients in clinical trials, some have been harmed by taking part. Also, it is possible that patients who are seriously ill may receive an inferior treatment.

Dr Bradley cited a study into the effects of multi-sensory stimulation for people with dementia (Baker et al. 2003). The aim of the study was to assess whether multi-sensory stimulation has more impact on the behaviour, mood and cognition of people with dementia than other activities such as playing cards or doing quizzes.

The study involved 136 people in three countries (UK, the

Netherlands and Sweden). The study found that there were limited short-term improvements for the two groups both during and immediately after the activities. However there were no significant differences between the groups in changes in behaviour, mood or cognition. The study concluded that multi-sensory stimulation was no more effective than other activities in the short or long term.

Dr. Bradley said that evidence is only meaningful when it combines knowledge of the patient with clinical knowledge. Care must be personalised, taking account of patient choice, giving the patient control over care decisions and importantly, dignity. Using the best available clinical evidence, individual clinical expertise and taking account of the patient's values and expectations is the way to improve patient outcomes.

In summary, she said healthcare staff must ask whether the research is robust and can be trusted, whether it is ethical, whether it provides answers, is meaningful, relevant and will lead to improved patient outcomes.

Workshop 2

In this workshop Michelle Meehan and Julia Lowe explained some of the pioneering work of Broadening Choices for Older People (BCOP) in creating the right environment for sensory stimulation. BCOP is a not-for-profit organisation set up in 1946 which employs more than 400 people and works exclusively with people over the age of 60.

The organisation owns and manages more than 500 properties, which provide dementia, nursing and residential care, as well as supported housing, extra care housing and independent living. They aim to create stimulating yet calming environments, encouraging reminiscence as well as social interaction.

BCOP first began to develop work on 'sensory stimulation' in the 1960s to help people with learning disabilities. They then wanted to extend the benefits of sensory stimulation to people living with dementia and other mental illnesses. They carried out research that involved visiting care homes and nursing homes in the Netherlands.

As a result of this research BCOP developed pet farms and a 'sensory street'. This street is a type of museum, with original phone boxes, petrol pumps, a post office, a sweet shop with jars of old fashioned sweets and a tearoom serving tea and cakes. They say residents get great pleasure from walking down the street and holding street parties. It is a kind of 'real life' therapy which helps take away the feeling of being stuck with a nursing home.

The sensory experience is crucial to BCOP's work. Their aim is not just to meet the basic needs of the residents, but to make sure they feel safe, secure and have a sense of wellbeing. Because memory loss affects every person differently, they consider each individual in order to provide them with appropriate cognitive stimulation.

Michelle Meehan, Lead Activity Co-ordinator, described the importance of creating the perfect environment for residents from the moment they wake up. Rooms are personalised so that residents feel 'at home'. She said that by making a number of simple adjustments to the environment they were able to create a more homely as well as a more stimulating living experience for residents.

She described how, by making adjustments to lighting and heating, colour schemes and signage, fixtures and fittings, flooring and general layout, it is possible to reduce residents' confusion and irritation and to improve both their mood and the quality of their lives.

The 'Dining Experience' introduced in all homes at lunch and tea time involves having one area of the home where residents can quietly enjoy a full dining experience, with table clothes and wine if they wish. Afternoons tend to focus on calmer activities such as visiting the library, reading or watching a film.

Julia Lowe, Environmental and Horticultural activity co-ordinator described the opportunities for activities on the pet farm. She said that older people gained a great deal of friendship and compassion from animals. Many people grew up with animals so spending time with them produces positive memories, and has a very and calming effect.

Residents can also take part in gardening and horticultural activities indoors as well as outside. Residents can sow vegetable seeds, pot them and watch them grow then harvest them and feed them to the pet animals. She explained that these activities help people to relax, encourage conversation and give people a sense of purpose and a sense of wellbeing.

Workshop 3

Dr Claire Garabedian, Associate Researcher in the Creative Arts and Dementia from the Association for Dementia Studies (ADS) within the University of Worcester, explained how music can enhance the lives of people living with dementia as well as those who support them.

She said that music can be a part of today's dementia care, which has progressed from caring for the body left behind, to ensuring that people who have dementia live as well as they possibly can.

Dr Garabedian spoke of human beings having five basic needs the need for comfort, to have an identity, to be occupied, to feel included, to experience attachment – all

underpinned by love (Kitwood 1997). She said that health care staff can relate to people with dementia in such a way that reinforces rather than undermines these basic human needs.

Research has shown that people with dementia need to feel close to others but lack the capacity to communicate this need. This in turn can lead care staff, friends and family to withdraw, creating a downward spiral.

Dr Garabedian stressed the importance of acting in a way that shows respect for the person with dementia, which enables them to feel valued, even honoured. She urged health care staff to try to see their own actions from the perspective of the person living with dementia. Do they build the person's confidence and reassure them that they are not alone?

She explained how the arts can bridge what she described as a 'personhood nurturing gap'. She said music can create a 'haven' because it is mobile and can sonically transform the listener's environment. Familiar music can transport the person to a place or time which enables them to recall or relive happy memories.

She said that as a means of non-verbal communication, music can be viewed as a universal language, transporting the person through time, and relieving all types of pain. The fact that sound is one of the last senses human beings are able to respond to means it is especially important to continue to offer music to people up to the moment of death. She cited Khan (1996) who said that, 'Sound has an effect on each atom of the body, and each atom resounds.'

Her thesis entitled, 'I'D RATHER HAVE MUSIC!': the effects of live and recorded music for people nearing the end of life with dementia living in care homes, and their carers ', explored the impact of music on people nearing the end of their lives who were considered 'beyond responding'. Among the techniques she employed were 'entrainment' and the 'ISO principle'. These techniques entail matching the tempo/mood of the music to the current state of the listener to capture his/her attention, then gradually moving the music in a direction that might lead to a fuller sense of wellbeing.

Dr Garabedian concluded by suggesting that there is a great need for development of a unified basic training for music practitioners, and greater funding for continued research into the most effective ways of using music with people living with dementia.

Conclusion

The workshops created genuine learning in a collaborative atmosphere: each prompted many questions from the audience and the sharing of practice across a variety of healthcare settings. There were staff from acute Trusts in attendance keen to learn from the BCOP experience and implement their ideas in an acute setting. There were staff from other nursing homes appreciative of the evidence from the experiences outlined by the workshops which enabled them to take ideas back to their workplace and share their learning.

Although research evidence to support sensory stimulation activities is developing, there is a lack of evidence surrounding the long term benefits of engaging with them, however the anecdotal evidence from the workshops was clear. Whatever the activity, it should be applied in the context of the needs of the individual, taking into account clinical need and promoting dignity at all times. Older adults experience an improved quality of life through engaging with sensory stimulation activities and whether this is evidenced or not, any perceived or actual improvement in quality of life has to be of benefit.

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Men and the early detection of Cancer – is it possible to identify who may need more support?

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Abstract

Background: Men have poorer health outcomes than women, and cancer is more common in older people (with incidence increasing with age for most cancers). The early detection of cancer can lead to improved survival, but the diagnostic phase is believed to be the most stressful time. Communication around the time of a diagnosis of cancer for men is difficult and tense: it is well documented that those in the early detection stage of cancer have high levels of distress, manifested primarily by anxiety. Being connected, having strong social support and receiving a person-centred care approach within this phase are beneficial and imperative (as the ability to cope may not be obvious or communicated).

Objective:
Research is being conducted to explore the introduction of new generic blood tests which should improve early detection of cancer. For that cohort of patients, waiting for results and a final diagnosis will be stressful, as will ongoing surveillance. For certain predisposed groups of men, the stress experienced in this waiting time has the potential to be exacerbated by a number of different factors. This paper explores which groups of men are more at risk, due to circumstances or life stage, and highlights the scope for future work to understand further how stratifying high risk groups of older men in particular can offer opportunity to identify interventions designed to support segmented groups.

Keywords
Early detection, Men, High risk, Social isolation, Peer support

Introduction

Background

Cancer is more common in older people, with incidence increasing with age for the majority of cancers (NHS England, 2016). Older people, aged over 70 years, make up over half of cancer diagnoses (ONS, 2016), and it is predicted that by 2040 people over 65 years old living with and beyond cancer will make up nearly a quarter of the population (Maddams, Utley and Møller, 2012).

Detecting cancer at its earliest stage is recognised as an important component to good prognosis and optimum survival. However, it is well documented that early detection rates in the UK are lower than many other Western countries, and remain poor in comparison (Elliss-Brookes et al., 2012). Cancer in older adults is less likely to be detected early, and emergency presentation diagnoses increase proportionately with age (PHE, 2015). Nearly half of all cancers in those aged 85 and over, in the four years leading up to 2010, were diagnosed after an emergency presentation (compared with the group aged 50-59, who account for 15% of cancers) (PHE, 2015) and often with late stage disease (Elliss-Brookes et al., 2012).

It is imperative to detect cancer early, as late diagnosis is associated with poorer outcomes (NCSI, 2013). Improved cancer support is also a financial necessity (DH, 2011) since, for example, colon cancer treatment costs increase from £8000 at stage 1, to up to £12,519 at stage 4 (Incisive Health, 2014).

For the general population, opportunities for early cancer detection are limited to either cancer screening programmes or incidental radiological findings. However, the three screening programmes in England — cervical, breast and colorectal (bowel) — do not recall older age groups (generally 70 years and above), as research indicates it is less effective and leads to overdiagnosis, causing more harm (Bulliard and Chiolero, 2015). Conversely, the British Geriatric Society state that evidence is lacking and that more research is needed to justify the exclusion (Quarini and Gosney, 2009).

Research is being conducted to explore the introduction of new generic blood tests which should improve early detection, while extending significantly the population of patients identified ‘at risk’ or living with early (pre-symptomatic) cancer (Cree, 2011). For that cohort of patients, waiting for results and a final diagnosis will be stressful, as will ongoing surveillance (Brocken et al., 2012). For certain predisposed groups, this stressful waiting time can be exacerbated by a number of different factors. This article explores this time period, considering men at certain life-changing points, as well as particular groups who are deemed to be high risk, and identifies where interventions could be designed to support men during the early detection stage.

Prediagnostic stage

The diagnostic phase is believed to be one of the most stressful times of illness (Poole & Lyne 2000, Lebel et al. 2003), and it is well documented that those in the pre-diagnostic stage of cancer have high levels of distress, manifested primarily by anxiety (Bugbee et al., 2005; Lang et al., 2006; Montgomery & McCrone, 2010).

There is a period of time, before diagnosis, when there is reflection on a shift from good health to the possibility of serious ill health (without looking or feeling ill and possibly with no symptoms) which creates tension between the two opposing states (Putman et al., 2004). The perceived 'threat' of a diagnosis can: challenge an individual's well-being; force an individual to confront their own mortality and fragility, and; evoke uncertainty about the future (Shaha, 2008). Mishel (1988) conceptualises uncertainty as "the inability to determine the meaning of illness-related events…. a cognitive state created when the individual cannot adequately structure or categorize an illness because of insufficient cues" (Smith & Liehr, 2003, p. 25). Feeling uncertain about the best course of action or which choice to make may fuel and perpetuate emotional reactions such as anxiety or depression (Houldin, 2003).

As the number of people within the diagnostic stage increases (in line with current trends), there will be more people living with uncertainty and heightened anxiety for longer periods of time, as waiting can vary greatly in terms of days to months. Although this gap has been acknowledged as a distressing time, the work in this area has concentrated primarily on breast, gynaecological and prostate 'watchful waiting' screening periods (Zisman, 2001; Lebel, Jakubovits and Rosberger, 2003; Awsare, 2008). It is recognised that there is still insufficient research looking at the period of waiting for a diagnosis (Lang, Berbaum and Lutgendorf, 2009; Irving 2001). Despite the fact that some studies show that pre-diagnostic experience has the potential to affect both diagnosis and post-diagnosis periods (Widerman 2004; Drageset & Lindstrøm 2005), it is still largely unknown what long-term implications these heightened levels of distress have. It could be argued that this under-researched area not only holds opportunities to enhance patient experience, but also has the potential to affect clinical outcomes and health economics. There is a need for further investigation regarding the extent to which the level of distress experienced impacts upon the individual and those around them.

In order to support the management of feelings and emotions, people need to be made more aware and referred to the evidence-based strategies and techniques available. Risk stratification offers the opportunity to predict groups of patients who may be more at risk of developing heightened (and potentially sustained) anxiety during the pre-diagnostic phase. For such patients, awaiting confirmation of results and a final diagnosis will be stressful, as will ongoing surveillance (Brocken et al., 2012).

Gender inequalities – why are men more at risk of unmet need?

It is well documented that men have poorer health outcomes than women (Wilkins, 2011). In the UK, men are more likely to: be overweight or obese (65% of men, compared with 58% women) (NHS Information Centre, 2010); drink alcohol in excess (22% men drink above the recommended limit, compared with 16% women) (NHS Information Centre, 2009a); have a poorer diet and understanding of nutrition (Wilkins, 2007); smoke (Robinson, 2009), and; be less likely to use primary care services (NHS information Centre, 2009b).

The latest statistics show that on average a male in the UK will live just under 4 years less than a woman (life expectancy at birth for men is an average 79.1 years, whereas for women it is 82.8 years) (Office for National Statistics, 2015). This gap is consistent across the socio-economic groups and even wider at lower levels. The Men's Health Forum reported that men experience a wider social gap in health than women (Wilkins, 2007) and men are reluctant about accessing healthcare services (White, 2001; Banks, 2001; Gough, 2013) and present at the later stages of illness or when it becomes critical (European Commission, 2011).

Although acknowledged as individuals, and not a homogenous group, there is a general reluctance from men in lower socioeconomic groups to engage with their health, and premature death is more pronounced (Wilkins, 2013). It is well evidenced that some men are more likely to conform to the historic masculine stereotype of men's perception of the need to be: strong; stoic; and macho (Wilkins, 2013). There is a perception that being big equates with manliness and masculinity, therefore certain men can be resistant to healthy eating messages, viewing healthy food as 'unsubstantial' and 'girlie' (Wilkins, 2011, 2013). Men with poor lifestyles are at risk, being more likely to be obese or overweight (Wilkins, 2011, 2013). A lack of comprehension of medical terminology potentially limits the ability of some men to actively engage or consider their health. A recent study (Wang, 2013) found that only 5% of low income, inner city men understood the function of the prostate (and only 15% and 19% respectively understood the terms 'incontinence' and 'urinary function').

Lifestyle choices also make certain groups more disadvantaged. For instance, men in the Gay, Bisexual and Transgender (GBT) community have higher smoking rates than the rest of the population (Johal et al., 2012). There is a wealth of research that indicates that gay men are more likely to experience distress, linked to "coming out", stigma and homophobia (Varney, 2010), and are more likely

than heterosexual men to attempt suicide (Wilkins, 2011). They are also at risk for certain types of cancer, including prostate, testicular and colon, and are at increased risk of developing some cancers. For example, men who have sex with men are 17 times more likely to develop anal cancer (CDC, 2010). Perceptions of stigma and disclosure are still issues that prevent the access of services for gay and bisexual men (Walter et al., 2006).

There are cultural barriers for men from BME communities, as they are less likely to seek help overall because of: language barriers; a lack of a sense of identity and community, and; reluctance from families around aspects of support such as counselling (Johal et al., 2012). There is also a perceived stigma from certain communities to seek help for mental health issues (Wilkins, 2013) and fatalistic attitudes towards cancer.

It is acknowledged that communication around the time of a diagnosis of cancer for men is difficult and tense (Bisson et al., 2002; George and Fleming, 2004). Men are faced with a dilemma in their communication with others at this stage (Lepore and Revenson, 2007). Studies have found that some men choose to keep the potential diagnosis to themselves until they have more information, others may reveal some elements (to close friends and relatives), and others may be open and share with everyone (Bloch et al., 2007).

Why are older men more vulnerable? - *Transitional life points, vulnerability and peer support*

With older age comes the increased experience of loss. The likelihood of death of family and friends increases and becomes a more a common experience in later life. There is also a loss of role when employment comes to an end which may also result in a decline in income and material comforts. As a result of age, life-changing events pose a general threat to men's health and are important to consider in relation to thinking about men more at risk or more vulnerable than others during the waiting period. Older men are less likely to have their mental health problems diagnosed, and the detection and treatment of depression in older men remains poor (MIND, 2011). There are high levels of need linked to bereavement, caring responsibilities and retirement (Johal et al., 2012):

The period of retirement - although for many men it is a time of recreation and pleasure, for others retirement brings a sense of a loss of purpose and worth (with potential exacerbation if retirement has not been made out of choice) (MIND, 2011). This may be attributed to personal failure, resulting in problems with identity, feelings of helplessness, a lack of control and depression (Möller-Leimkühler, 2003). Men feel vulnerable when faced with the prospect of loss without having the protection of social connections to provide support, a strategy frequently used by women (Möller-Leimkühler, 2003).

Becoming widowed, separated or divorced – poses a major risk for social isolation and loneliness, as men are more likely to have their social networks curtailed and lose touch with their children and grandchildren (Ghate et al., 2000). Research indicates that having a partner is a key influencing factor regarding men's health - unmarried men are less likely than married men to receive Prostate-Specific Antigen (PSA) testing (Walter et al., 2006) - this may be due to a lack of primary relationships that support and encourage health seeking behaviours (Cohen et al., 2000). The reasons for this are that partners: are a source of support and encouragement to persuade their male partner to visit the GP or proactively seek information on their health (Bogel, 2014); protect against the minimalizing or deterioration of social networks (losing touch with children and grandchildren especially in later life); protect against social isolation in later life (Johal et al., 2012).

Becoming a carer - by the age of 75 years, men are more likely to be carers than women (MIND, 2011). Men often miss out on valuable carer support (as often caring is viewed as a 'women's role') as they are less likely to identify themselves as one (Johal et al., 2012). One study found male carers to be socially isolated: 56% identified caring had a negative impact on their mental health; 40% reported never having a break from their caring role (Carers Trust, 2014).

The potential impact of these life transitions is social isolation, and having few connections brings negative health consequences. Studies have shown links between isolation and a greater risk of: cognitive decline (James et al., 2011); lower self-esteem (Steptoe et al, 2004) and depression (Cacioppo et al., 2006); defective immune functioning and higher blood pressure (Grant et al., 2009; Hawkley et al., 2010); and suicide in older age (O'Connell et al., 2004). Consequently, strong social connections, including family and friendships (Richmond et al., 2011), have a significant impact on life expectancy, improvements in health and quality of life (even after accounting factors such as smoking, gender and ethnicity) (Holt-Lunstad et al., 2010). Being connected is likened to: giving up smoking; healthy eating; and lowering blood pressure and cholesterol (Hawkley et al., 2010; Holt-Lunstad et al., 2010). Peer support has been found to reduce emergency admissions into hospital (De Silva, 2011), improve medicine compliance (DiMatteo, 2004) and adherence to other treatments that improve health (Heisler, 2007). A recent research programme identified that befriending schemes are a significant preventative intervention in mental health, with potential cost savings of £270 per person for every £85 invested (when quality of life measures are included) (Knapp et al., 2011).

Peer support, and a 'sense of mastery' (linked to a sense

of control), help to regulate the impact of stress on health as they help to disrupt the relationship between stress and distress (Aneshensel, 1992; Pearlin, 1999; Dohrenwend, 2000). The growing area of support is the online community. Online peer support offers an opportunity to overcome barriers to uptake of support (such as isolation and stigma). Research into online interventions for people affected by cancer is beginning to be looked at in more detail (Beatty et al., 2011; Duffecy et al., 2013; Leykin et al., 2012; van den Berg et al., 2013), but this generally relates to the survivorship stage. Nevertheless, the effectiveness of mental health online interventions has been well documented (Barak et al., 2008; Griffiths et al., 2010). There is, therefore, opportunity to build on previous work and look with 'gender lenses' at the needs of men during the early detection of cancer.

Conclusion

It is accepted that waiting for results will always be demanding, as it presents men with the opportunity to reflect upon potential threats. Time is spent considering the outcome, managing uncertainty, and experiencing feelings of not being in control (Greene et al., 2012). Communication around the time of a diagnosis of cancer for men is difficult and tense (Bisson et al., 2002; George and Fleming, 2004).

Perceived devaluation can result in stress and distress (Major and O'Brien, 2005), but being connected and having strong social support is beneficial. Therefore, peer support is imperative when looking to address the needs of men who are more predisposed to vulnerability and risk due to the uncertainty, worry, fear and anxiety that can be experienced during the early detection of cancer. It is important to consider a person-centred individual approach to this phase, as the ability to cope may not be obvious or communicated.

It is acknowledged that there are certain groups of men who are at higher risk of need due to their circumstances (for example: not having a partner; having significant caring responsibilities; being from a BME or GBT community). This overview has highlighted the scope for future work to understand further how stratifying high risk groups of older men can offer opportunity to identify interventions designed to support segmented groups. There is space and opportunity for future support to be developed for men during the early detection stage of cancer.

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A literature review on the ethics of surveillance technology

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Surveillance has been part of our society for many centuries. Dobson and Fisher (2007) argue there have been three major waves of surveillance: firstly, the eighteen century reformer Jeremy Bentham's panopticon, secondly Orwell's Nineteen Eighty-Four and finally, current day surveillance technologies in which there has been unprecedented growth in recent years.

Ball et al. (2006) on behalf of the Surveillance Studies Network (SSN) published a report which gave a definition of surveillance as: 'Where we find purposeful, routine, systematic and focused attention paid to personal details, for the sake of control, entitlement, management, influence or protection, we are looking at surveillance.' The SSN also popularised the term that sociologist Marx used in the mid 1980's 'surveillance society' and warned that surveillance was pervasive within the UK. Wright et al (2015) suggest most people are unaware of the extent of surveillance on their lives and there is little public debate about its effects. However, within the context of modern healthcare, certain surveillance technologies are being considered as enablers to care and as such the ethics of the use of surveillance technologies within healthcare is worthy of consideration.

Background

It is argued that the early development of surveillance began with a building design by Bentham. It was built for optimal surveillance with only one inspector being able to observe all the occupants: the design was used for prisons and was called a panopticon which means all-seeing (Dobson and Fisher, 2007). The structure enabled the visibility of inmates from a central tower however, the inmates were unaware of whether guards were observing them or not. The theory underpinning the panopticon was to promote discipline through expected behavioural norms and reflection on their own behaviour to transform prisoners as they felt under constant surveillance (Haggerty and Ericson, 2000).
Into the 20th century, Orwell wrote in clairvoyant fashion about citizens being monitored in their homes by a device which records their behaviour and projects images to enforce tyranny. As Haggerty and Ericson (2000) point out we still hear cautions about 'Big Brother' yet his dystopic vision has been transcended due to the rapid development of computers and optics. Both the sociologist Weber and philosopher Foucault criticised the panopticon with Foucault drawing on its nature to exploit a power relationship to enforce discipline whereas Weber related surveillance to bureaucracy and its impact on society (Ball et al., 2006).

Modern surveillance technologies include Closed Circuit Television (CCTV) and Global Positioning System (GPS) tracking and within the healthcare arena; personal health monitoring and assisted living technologies have been developed to enable people to live at home for longer and assist healthcare professionals in caring for older people. Haggerty and Ericson (2000) assert that the panoptic metaphor needs rethinking in light of modern surveillance technologies however, healthcare views technology as a potential solution to alleviate the growing pressures of protecting and caring for an expanding and increasingly elderly population (Niemeijer et al, 2010).

The rationale for each method of surveillance is distinct: Bentham's was the utopian perfection of society; Orwell was the enforcement of tyranny through television monitoring and modern surveillance in today's society it is for security and safety. Despite claims that modern surveillance technologies are for safety and security, Dobson and Fisher (2007) argue that their root functions are total surveillance, discipline and control and they represent the third generation of panopticons. The view that surveillance supports discipline and control suggests that electronic surveillance constrains people's liberty and privacy (Essen, 2008).

Monitoring by surveillance raises questions about ethical issues, namely: privacy, autonomy, dignity and independence thus prompting this literature review to identify the themes related to the ethics of surveillance technologies with a particular focus on privacy and consent.

Literature Search

A search for relevant literature accessed the library databases CINAHL and Medline to identify, quantify and examine the published literature on the ethical issues surrounding the use of surveillance technologies. Key words such as 'surveillance', 'monitoring', 'lifestyle monitoring' in combination with 'ethics' or 'ethical' were used to identify the relevant literature. Eight published studies were analysed to enable illustration of the key factors in response to the ethical debate among healthcare professionals and ethicists around surveillance technology as to whether it is an infringement of human rights and contrary to human

dignity as it reduces or impinges privacy and removes personhood (Niemeijer et al., 2016; Minuk 2006). It has to be noted that the majority of articles accessed were literature reviews which indicates the lack of empirical research in this area and is an obvious limitation of this review.

Findings

In 2011, the Department of Health published the headlines from one of the biggest, most complex studies undertaken by the government. The Whole System Demonstrator (WSD) programme was launched in May 2008 and was conducted as a randomised control trial of telehealth and telecare to examine whether the use of technology as a remote intervention makes a difference. The sample populations involved 6191 participants across three UK counties. The telehealth trial had 3030 participants with diabetes, heart failure or chronic obstructive pulmonary disease. The telecare population were selected using the Fair Access to Care Services criteria. Each county used different surveillance technologies but all aimed to examine the same research question. Participants with cognitive impairments could be recruited into the trial if they had a carer who could assist them to use the technology.

The Department of Health (2011) define telehealth as the use of electronic sensors or equipment that monitor vital health signs remotely which are monitored by an appropriately trained person who can make decisions about potential interventions in real time to prevent admission to clinic or a hospital. Telecare is defined as personal and environmental sensors in the home to enable people to remain safe and independent, should an event occur the information is acted upon immediately with the most appropriate person responding to the information.

The early headlines from the study indicate positive outcomes with statements such as 15% reduction in A&E visits, 20% reduction in emergency admissions, 14% reduction in elective admissions, 14% reduction in bed days and 8% reduction in tariff costs (DH, 2011). The study claims to demonstrate a 45% reduction in mortality rates. Further papers (Steventon and Bardsley, 2012; Steventon et al. 2012; Henderson et al., 2013) have since been published looking at mortality rates and cost effectiveness but there has been little written about the ethical issues encountered. Whilst the results appear encouraging, no detail has emerged as to how the ethics of undertaking the study were considered or the ethical issues that arose out of participants engaging with telehealth and telecare especially including the involvement of cognitively impaired individuals.

In 2015, The Social Care Institute for Excellence (SCIE) conducted a literature review on the use of video and associated technology in health and social care settings on behalf of the Care Quality Commission. The report discusses the range of technologies now available including video surveillance, assistive technologies and telecare e.g. alarms, monitors and sensors and web-based technologies. Mortenson et al. (2013) state that older people have been exposed to surveillance within institutional settings but not non-institutional spaces such as their homes or communities. They typologise the discourse around surveillance associated with ambient assisted living (AAL) which aims to keep the patient at home rather than in hospital. One of key discourses is on rights which focus on the individual's right to privacy in relation to the protection of personal data generated by surveillance. It considers whether keeping the patient at home rather than in hospital compensates for the loss of privacy (Wild et al. 2008). There is the technical discourse which focuses on what the system does and how it does it. The systems are designed as problem solving solutions (the what) and are adapted according to the persons capabilities (the how). Finally, there is the managerialist discourse which discusses the importance of efficient management of a scarce resource as an essential goal, with healthcare staff being considered as a scarce resource. One of the primary goals of AAL is to keep the patient at home therefore avoiding any unnecessary and expensive hospital stays.

In 2008, Wild et al. conducted a qualitative study on unobtrusive in-home monitoring. Six focus groups were established, three for older adult participants and three for family members or carers. In total 23 older adults' participated and 16 family members or carers. The aims of the project were to identify the needs and views of participants and their family members or carers towards in-home monitoring. The participants did not actually use in-home monitoring; they were presented with examples via slides and pictures and asked to consider whether the information on monitoring was interesting and something they would engage with. This perceived rather than actual experience is an obvious limitation of the study.

Four themes emerged: maintaining independence, detecting cognitive decline, sharing of information and the balance between privacy and the perceived benefits of monitoring. Overall participants expressed interest and willingness towards unobtrusive in-home monitoring although this was closely linked to who would look at and use the data generated by such systems with some asking if their own doctors would be able to view the data.

A different form of surveillance is video surveillance or what is often referred to in America as granny cams which have stimulated legal debates around the issues of safety and privacy (Cottle, 2004; Bharucha, 2006; Niemeijer et al. 2010). Cottle (2004) writes an opinion piece in the Elder Law Journal exploring the positive and negative aspects of granny cams which are already widely used in elderly care. Supporters of granny cams state their introduction has been essential in restoring public confidence in the care home industry which has been cited for abuse and

neglect however, nursing homes are often resistant to their introduction based on issues around privacy, fear of litigation and increased staff turnover (Cottle, 2004; Bharucha, 2006).

Cottle (2004) concludes that American states that authorise granny cams offer safe care and benefit nursing home residents and their families, she goes on to propose that all American states should legislate for granny cams. However, she does not advocate for the compulsory use of cameras as the choice should be the right of the resident but all residential nursing homes should be able to offer the technology.

Mittelstadt et al. (2011) conducted a literature review into the ethical issues associated with personal health monitoring (PHM). Personal health monitoring involves an electronic device or system to continually monitor a person's health outside hospital. They reviewed 39 papers on ethical issues relating to PHM and identified eight common ethical themes: privacy, visibility, medicalisation, social isolation, autonomy, balance of principles, informed consent and development and the impact on healthcare providers.

Two issues were raised around privacy: personal privacy and data privacy. Personal privacy was centred on the issues of being monitored by a third party and this intrusion on daily life. Data privacy was examined as the ability to have ownership over the data produced so it cannot be used incorrectly by third parties. A discussion was had as to whether the current Data Protection Act (1998) actually covers the type of data generated by surveillance technologies and raised this as a key concern for the future. Visibility concentrated on the awareness of the surveillance device in terms of whether it could be seen by others and its portability. An interesting point made about visibility was that PHM's are generally designed to be inconspicuous to promote acceptance of the technology however, older adults with increasing cognitive impairment may grow accustomed to the technology and forget about it which could lead to covert surveillance consequently raising questions of consent (Bowes et al., 2011).

Medicalisation suggests the presence of technology acts as a constant reminder to the user of their medical condition in their home environment. This could potentially lead to a blurring in distinction between home and hospital if surveillance technologies continue to develop. It also has the potential to highlight frailty as the user knows they require medical monitoring which could also lead to stigmatisation.

If PHM is considered as a safety mechanism there is a concern that it could lead to social isolation. Daily monitoring of the user may lead to a lack of visitors or medical/care staff due to the fact there may be less responsibility to interact with the user. This could be detrimental to overall health as social interaction and physical touch are both considered health benefits (Chan et al., cited in Mittelstadt et al. 2011). An issue highlighted in regards to autonomy was the over reliance on surveillance technologies leading to the participants not looking after themselves as well as they could. Another concern regarding autonomy was that certain decisions may be taken out of the participants hands as medical staff can call for help remotely without discussing any emergency issue with the participant first. The balance of principles relates to what is perceived as a dichotomy between the views of participants in relation to surveillance technology. As mentioned previously this relates to the ethical conflict between freedom and safety implying a balancing act between the need for technology to support an individual whilst potentially impinging on their privacy.

Mittelstadt et al. (2011) identify several studies that discuss informed consent and development. These studies generally agree that valid informed consent cannot be gained as until the participant uses PHM it is not known what the implications of its usage will be. The impact on healthcare providers included: a deskilling of the workforce in human interaction and recognition of non-monitored symptoms, a change in power relationships and potential job threats as surveillance technology takes over routine daily tasks.

Mittelstadt et al. (2011) conclude that the papers they reviewed lacked discussion around the ethical issues of the development and implementation of PHM technologies. They call for further research to be conducted before the technology becomes common practice to ensure it is being used in a beneficial and ethical manner.

Essen (2008) conducted a qualitative study involving 17 older adults in Sweden who were interviewed during a telemonitoring project which involved being continuously monitored for activity in their own homes in order to explore the effects on the older adult's liberty and privacy. The findings described 16 out of 17 older adults had a positive experience of being under surveillance through telemonitoring. The reported benefits included feeling safer, viewing surveillance as an enabler to stay at home and that care personnel were interested in gathering data about them and could intervene. When asked about privacy, they did not view surveillance as an invasion of their privacy compared to their concerns of being admitted to hospital or a care home. They viewed admission to such institutions as a greater invasion on their privacy as they would not be able to leave and find their own private spaces and they did not want to be 'forced to watch people that cannot manage themselves' (p. 132).

Essen warns of the fact that older adults perceived the telemonitoring as offering better individualised care and were perhaps uncritical and unquestioning of the nature

of surveillance. She states a limitation of her study as the participants being grateful for modern technologies to monitor them and involvement in a development project which potentially led to overly positive responses. However, Essen's assertion that older adults views of privacy are generally related to the local or physical element of privacy and freedom from observing and reacting to others rather than information privacy challenges the views of some authors that believe surveillance is conducted against the publics will and perceived it as a threat to privacy (Haggerty and Ericson, 2000; Dobson and Fisher 2007).

Niemeijer et al (2010) utilised a concept mapping technique with a range of healthcare professionals and ethicists to explore how surveillance technology is viewed and how it might be best applied in a residential setting for people with dementia and intellectual disabilities. They developed three themes and each had three sub-themes. The first theme was institutional aims and within this they categorised functional efficacy, safety risks and staff burden. The next theme was care relationships and this included duty of care versus autonomy, substitution of care and person centred care. Finally, there were residents' concerns and this theme included freedom and consent, dignity and stigma and privacy.

The categories identified closely reflect Mittelstadt et al.'s (2011) eight themes although the focus of the literature reviews differed in that Niemeijer et al. (2010) focussed specifically on dementia and intellectual disabilities rather than personal health monitoring which aimed to facilitate keeping older people at home for longer whereas Niemeijer et al.'s review incorporated in-patient and care home residents.

Niemeijer et al. (2010) begin their discussion by stating that despite their systematic thematic analysis, they were not able to reach consensus as to whether or not surveillance technologies are an ethically viable option in the formal care of people with dementia or intellectual disability. The warnings from the study centre on the plea not to reduce the ethical debate to safety versus autonomy but to consider avoiding stigmatisation, enhancing freedom, respecting privacy, dignity and autonomy and catering to the resident's individual needs (pg. 1139).

Bowes et al. (2012) conducted a literature review considering the ethical implications of lifestyle monitoring data (LMD) in ageing research and considered key concerns around informed consent, working with cognitively impaired older people and the issues around surveillance of the process of care. They suggest that the approach to analysing ethical issues is to separate out the meaning, context and conditions of each activity using a set of questions to explore the validity of the intervention and to seek out whether the surveillance technology measures what it is supposed to measure.

The study identifies four generations of telecare systems for healthcare surveillance with the first generation being in-house alarms or call bells which required the user to be able to activate them. Second generation systems started to embed the technology and these could be linked from smoke or gas alarms through to alerting medicine dispensers and continence monitors. Lifestyle monitoring data is considered a third generation telecare system which can identify movement and gait, dispense medicine including prescription reminders, medical monitoring devices such as bracelets or vests which provide 24-hour continuous medical monitoring. Fourth generation systems are currently being developed and include under skin sensors so participants do not need to wear a LMD device and the use of robots to assist with housework.

Discussion: Privacy

Mittlestadt et al. (2011) discuss two types of privacy: personal and data yet Allen (1995) outlined three interconnected aspects of privacy. Firstly, information privacy which enables security around access to personal information then decisional privacy which prevents intrusion in our decision making and finally, local or physical privacy which protects against invasion of personal spaces or areas. Essen (2008) goes on to consider the literature surrounding hospital patients' experience of loss of privacy and this relates to local or physical privacy at it is centred on the fact hospital patients cannot withdraw into personal spaces, the literature also identified the proximity of being faced with other people's problems as an invasion of privacy. Essen refers to this as freedom from observing and reacting to others (pg. 129). What also emerges from the privacy and care literature is that patients primarily desire privacy in relation to other patients rather than in relation to care professionals (Essen, 2008 p. 129). This is supported by Wild et al. (2013) who found that privacy concerns were less of an issue than anticipated as participants were willing to share their personal data with healthcare professionals as they perceived it would be of benefit to them.

Cottle (2004) notes that people who resist the introduction of granny cams argue that the nature of nursing care e.g. bathing, dressing and wound care leads to exposure and that to have these intimate care activities captured on camera is humiliating and unnecessary. This is identified by Bowes et al (2011) as the process of care and inquires as to whether it is ethically sound to use surveillance during care episodes. Bharucha et al (2006) examine 'zones of privacy' and go onto discuss the lack of statutes within the US to define what is public, semi-private or private indicating that there is a grey area within the law as to what constitutes privacy. Bowes et al (2011) question the level of dignity and respect experienced by patients with dementia and that historically they have experienced intrusions into their personal care for many years.

The issues highlighted around the elements of privacy suggest that primarily, consideration needs to be given to the need for surveillance and the proportionality of the intrusion into individuals' private lives by means of the surveillance measure (Wright et al, 2015). There is a balancing act between the need for technology and the potential of offering freedom and safety to support an individual whilst potentially intruding on their privacy. Equally, healthcare professionals must consider the privacy interests of all stakeholders affected by surveillance; from healthcare practitioners through to vulnerable patients and family carers and how the data generated by surveillance will be utilised. As the Data Protection Act (1998) does not necessarily cover all aspects of the data gathered through surveillance, urgent work needs to be done to redress this imbalance to ensure data privacy.

Consent

Mittelstadt et al. (2011) made the point that PHM's are designed to be inconspicuous so the technology does not interfere with daily living however, this does raise concerns regarding ongoing consent for older adults with cognitive impairment. This assumed consent due to the ongoing nature of the surveillance may lead to what Bowes et al (2012) state is covert surveillance.

Bowes et al (2012) raise key research ethic issues around informed consent and working with cognitively impaired older people. They recognise that the use of LMD can support people with dementia by detecting problems early, monitoring if they get lost and assisting them with activities of daily living. However, older people with dementia are probably least likely to comprehend, learn and consent to such surveillance technologies yet that might be the most likely to benefit.

The SCIE paper (2015) raised the issue of consent around communal and private spaces and whether consent is required in certain settings e.g. the individuals home. Consent is linked to privacy in terms of video surveillance in care homes where healthcare professionals, carers and visitors may be captured on cameras. Cottle (2004), Bharucha (2006) and Minuk (2006) warn that video surveillance in care home settings used as a deterrent to prevent poor care can be viewed as an invasion of privacy as not all captured on the camera footage may have consented. This can be confounded by granny cams where a resident or their carer has installed a surveillance monitor but the other residents, workers or healthcare professionals have not consented. However, there is less support for care home employees as certainly in the US, employment in the context of prior notification of surveillance technologies implies informed consent which leads to what Niejeimer et al (2011, pg. 1137) state as the recorded individuals 'reasonable expectation' of privacy or lack thereof (Cottle, 2004; Bharucha et al. 2006)

Conclusion

The ethical issues highlighted from conducting this review support many of the issues identified previously with this review focussing specifically on privacy and consent.

All of the papers reviewed call for further research to be conducted to promote discussion around the ethical issues associated with surveillance technologies. Bowes et al. (2012) discuss the lack of a sound empirical base around elements of control and loss of privacy. Essen (2008) warns of the ethical issue around the use of surveillance technologies in people's homes in that older adults are perhaps uncritical and unquestioning of the nature of surveillance and how it might impact on their privacy. However, there is the argument that surveillance technologies might help restore public confidence in the healthcare system (Cottle, 2004; Bharucha et al., 2006).

In the future, ethical issues surrounding the proposed fourth generation unobtrusive telecare systems being developed need to be discussed as there is the potential that this could lead to covert surveillance unless issues of privacy, consent or implied consent are fully explored.

To address privacy, informed consent and safety issues adequately, healthcare professionals must consider the decisional capacity of patients to consent and their right to privacy be that data, decisional and/or physical. Wright et al (2015) list a serious of questions that should be asked before people engage with surveillance technologies. The questions range from whether the surveillance is necessary, overly intrusive, benefits the participants, avoids potential harm, considers social consequences, has appropriate supervision of generated data and asks that the judgments made consider the consequences for the participants' human rights, freedom and democracy.

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How should nurses assess pain in people with advanced dementia?

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Abstract

Aim: This paper is a literature review conducted to investigate how nurses should assess pain in people with advanced dementia within acute settings and whether this should be through standardised pain assessment tools, clinical judgement or a combination of both.

Background: Pain in people with advanced dementia is commonly undetected or misinterpreted by nursing staff because these people are usually unable to verbally communicate.

Methodology: The databases CINAHL, ASSIA and Medline OVID 1948-present were used using a specific search strategy. Relevant papers were selected and were critically appraised to determine the strength of the evidence and the risk of bias to ensure that the soundest evidence was focused on the most within the review.

Results: Eight papers were identified following different methods of excluding papers. Three main methods were identified (1) Observational method (2) Clinical judgement in pain assessment (3) Standardised tools in pain assessment. Barriers to effective pain assessment are identified.

Discussion: There is limited evidence on assessing pain in people living with advanced dementia within an acute setting. The majority of the research relies on nursing home people typically with a mild or moderate diagnosis of dementia. Currently there is no established consensus on how to assess pain in people with advanced dementia in acute settings.

Conclusion: There are inconsistencies within the literature however, the main consensus seems to focus on pain assessment tools. This ambiguity suggests that further research is needed to ascertain how pain in people living with advanced dementia within acute settings can be assessed.

Introduction

Dementia is a progressive disease which is becoming more prevalent within the United Kingdom. Dementia is an umbrella term for different types of cognitive impairment: Alzheimer's, Korsakoff syndrome, vascular dementia or dementia with Lewy bodies. Dementia is an expression used to describe symptoms which may include memory loss, mood changes and problems with communicating and reasoning. Statistics show that in 2015; 850,000 people were living with dementia in the UK which is set to increase to 1 million by 2025 (Alzheimer's Society, 2014a). This increase is predominantly due to the ageing population meaning there are more people within the population who can be diagnosed with dementia (Alzheimer's Society, 2014b). The Royal College of Psychiatrists (2005) and Sheehan et al (2009) show that a significant proportion (around 30%) of hospital in people are people living with dementia.

This review focuses on assessing pain in people living with advanced dementia in the acute setting. Pain can be challenging to assess, for example in people with delirium, the unconscious people and people with any form of cognitive impairment (Paulson et al 2014). Dementia affects the brain which causes a cognitive decline; it can affect people' memory, personality, communication and judgement (Alzheimer's Society, 2015). However, dementia can be classified as mild, moderate and severe: mild dementia is characterised by difficulties with a person's memory or thinking which is usually worse than a healthy person of the same age and mild dementia does not significantly interfere with the patient's daily life (Alzheimer's Society, 2015). Moderate dementia means that people need more support to manage daily life. They need frequent reminders to eat, wash or dress and are likely to become increasingly forgetful (Alzheimer's Society, 2015). Severe dementia is expressed as a decline in cognitive function characterised by an absence of intelligible ideation and advanced dementia leads to memory impairment which is so severe that the person may forget their occupation, schooling, birthday, family and sometimes even their name (Byrne et al 2008).

McAuliffe et al (2012) state that people living with dementia experience incidents of pain equal to people who do not have dementia and suggest that pain assessment and treatment are inconsistent and inadequate for people living with dementia. It is therefore important to look at possible

strategies to overcome barriers to identifying pain in older adults with dementia (McAuliffe et al 2008). McAuliffe et al (2008) reported that the use of pain assessment tools led to more successful assessments of pain in older adults with dementia. However, one main finding implied that clinical staff were not utilising the pain assessment tools and were using their own clinical judgement instead.

Aims and objectives

The aim of this paper is to investigate effective ways of assessing pain in people with advanced dementia within acute settings.

Methodology

The databases Medline OVID, ASSIA and CINAHL were accessed to provide medical and nursing literature relevant to the topic of work. The Joanna Briggs Institute Library (JBI) (Joanna Briggs Institute, 2014) and Cochrane library were also used to source relevant literature.

The search terms included the following key words; dementia, dementia, acute setting, hospital, pain assessment, pain tool, pain, clinical judgment, assessment and cognitive impairment. In addition, the AND/OR combinations were used within the search strategy.

The inclusion and exclusion criteria comprised articles from the last 10 years, published in English and within the acute setting. The rationale behind choosing the acute setting was to explore the evidence of specific interest within this paper. Papers included nursing home people or people who were residing in long-term care units were excluded.

The papers were then critically analysed using the BestBETs checklist (Mackway-Jones et al 2015) to identify common themes and risk of bias to determine which were the most reliable in terms of addressing the papers aims.

Discussion

The aim of this review was to investigate how nurses should assess pain in people living with advanced dementia within acute settings. The literature gathered mostly follows the qualitative paradigm. Using qualitative research can produce an in-depth understanding of human experiences (Houser 2008). However, due to the subjective nature of qualitative approaches it can be difficult to apply conventional standards of reliability and validity (Houser 2008) nevertheless, an insight into what recommendations can be made for future practice should still be explored.

Literature reveals a lack of robust research regarding people living with advanced dementia. Much of the research is based on people with a mild or moderate diagnosis. Very few studies appear to have examined advanced dementia, which makes it difficult to draw valid conclusions. These people are typically more challenging to assess due to cognitive impairment meaning they struggle to participate in research, perhaps explaining the paucity of evidence. In comparison, cognitively intact service users can be assessed more quickly because of their ability to communicate, potentially resulting in increased involvement with research studies.

From reading the literature, various methods for assessing pain in people living with dementia were highlighted including observational, self-assessment, clinical judgement and pain assessment tools (Parmelee et al 1993, Epperson and Bonnel 2004, Doran et al 2006, Martin et al 2010, Herr et al 2011, Paulson et al 2014).

Types of pain assessment

Observational methods, whereby people with advanced dementia are assisted with daily activities and assessed for pain, can produce reliable results because they can be used to assess people with all types of dementia (Martin et al 2010). Martin et al (2010) suggest that client groups with a high incidence of communication impairment are dependent on nurses to make accurate interpretations of their communication as nurses are often best placed to observe service users.

Assessing pain can be achieved through self-assessment, interchangeably known as self-report. Self-assessment is a way of measuring pain which involves the person reporting when they are in pain. Papers within this review have suggested that some people with advanced dementia still have the ability to communicate through self-assessment. However, Herr et al (2011) state that the population of people unable to self-report is largely people living with advanced dementia. Nevertheless, they propose the use of self-report for service users capable of this.

Parmelee et al (1993) state that self-assessment from people with cognitive impairment are just as valid as those from people with no cognitive impairment. However, Horgas et al (2009) argue that self-assessment alone is insufficient for people living with advanced dementia because of their inability to communicate and suggest combining self-assessment with pain assessment tools.

Clinical judgement is another method used to assess pain. Nurses exercise their clinical judgement when assessing pain on an individual basis. Doran et al (2006) voice that significant variations can exist when nurses make decisions. These variations may happen when nurses rely on their own clinical judgement and complacency prevents them from forming their own opinions and judgements (Yang et al 2012). Yang et al (2012) also argue that nurses are sometimes overconfident regarding the accuracy of the judgements they make. If judgemental overconfidence occurs this can lead to incorrect and suboptimal decisions potentially resulting in incorrect pain assessments and therefore, undermanaged pain.

Nurses within nursing homes use clinical judgement because of greater knowledge they have of their residents. Husebo et al (2010) studied nurses who had worked within nursing homes for a mean of 5.9 years and found that nurses who knew the residents well did not use an alternative method of pain assessment. A survey of 68 UK nursing homes indicated that 75% of nurses did not use a standardised pain assessment tool (Zwakhalen et al, 2006).

This issue highlights the difficulty of applying nursing home study results to the acute setting. In acute settings, where there is a high service user turnover, the nurses would not know the service users well enough to know when they are in pain. Epperson and Bonnel (2004) propose commonly used pain assessment scales are the most beneficial way of evaluating pain in people who live with dementia. Feldt (2000) recommends that if a scale is identified it must be suited to the individual. It could be challenging to suggest a standardised pain assessment tool because some may be more applicable than others dependent on the clinical area. However, implementing a pain assessment tool across a whole acute setting could ensure that nurses become experienced in using the same tool.

There are potential barriers when completing pain assessments as nurses can mistake some manifestations of other traits, for example, depression and other psychological symptoms as pain (Cerejeira et al 2012). This can make pain assessment challenging. Cerejeira et al (2012) suggest that depression can exhibit similar symptoms to pain, such as, sleep and appetite disturbances.

As mentioned previously, much of the research was based in nursing homes or people residing in long-term settings therefore, extrapolation of study findings from research using nursing home residents should be applied cautiously to acute settings. Nursing home residents may experience chronic pain owing to the ageing process and the pathophysiology changes their experience as there is a common belief that aging and pain are linked (Zanocchi et al 2008). Most of this population within this setting suffer nociceptive pain and neuropathic pain although Wolf-Klein et al (1998) argue that pain is less prevalent in people with dementia because they suffer with fewer co-morbidities. However, Haasum et al (2011) propose that people with dementia do not suffer with any fewer painful conditions than those without dementia. The Wolf-Klein et al (1998) study is somewhat dated and it could be argued that more is known about pain in people living with advanced dementia. An increasing ageing population could also suggest that people living with dementia may have as many co-morbidities as those without dementia.

Barriers to effective pain assessment

Effective pain assessments could be made more effective if nurses receive good quality training specifically in relation to people living with dementia (Achterberg et al 2013). Inaccurate beliefs of pain assessment and poor knowledge are barriers to ensuring high quality care.

Poor staffing levels, staff attrition and a fast paced environment may also impact on the ability to assess pain (Melnyk and Morrison-Beedy 2012). Assessing pain in people living with dementia may take longer because pain tools take time to complete. Burns and McIlfatrick (2015) and Elcigil et al (2011) suggest poor staffing is a barrier to effective pain assessment. NICE (2014) have developed a nursing red flag system as correct staffing levels can impact greatly on patient safety and can determine whether they receive their fundamental care needs or not. The red flags ensure that staffing levels are safe within the clinical area at that time with regular pain checks being one of the red flags.

The see change: think pain campaign (2014) initiative was shaped to assist in pain assessment. A mnemonic was created to help nurses identify the signs that people living with advanced dementia might display when they are in pain. Jarzyna et al (2011) considered the American Society for Pain Management which recommend a comprehensive, hierarchical approach to pain assessment that incorporates a number of steps. These steps include asking people about their pain and using a standardised observational tool to assess pain. The American Geriatrics Society (2002) published guidelines on pain assessment in older persons with dementia. They recommend that an algorithm should be presented to assist the nurses in pain assessment.

Conclusion

The findings of the literature review convey and capture a general meaning of pain assessment in people living with dementia. This paper has considered themes in a wider context by looking at guidelines and barriers which may underpin pain assessment although, it has not been able to determine how nurses should undertake pain assessment in people living with advanced dementia within acute settings.

The literature has indicated that overall standardised pain assessment tools are perhaps the best way forward for acute settings to ensure that nurses make accurate assessments of pain and can therefore implement an appropriate pain management plan. However, there is still a shortage of evidence regarding people living with advanced dementia. Further research in this area is required to change practice and promote a more proactive approach.

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Dementia Care: how well are nurses equipped?

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Introduction

Dementia is a growing healthcare challenge, both nationally and internationally (Department of Health, 2013). Based on three key themes, 17 recommendations were made within the 'Living well with Dementia: a National Dementia Strategy' (DH 2009) around raising awareness and understanding, early diagnosis and support and living well with dementia. This was followed by the 'Prime Minister's Challenge on Dementia 2020' (DH 2015) which stated by 2020 every person with dementia would receive high quality, compassionate care from diagnosis through to end of life care in all care settings.

The focus of this paper relates to the first theme of the National Dementia Strategy (DH 2009) raising awareness and understanding in relation to nurses caring for people living with dementia.

Dementia itself is not a disease but is essentially an umbrella term used to describe progressive symptoms such as memory loss, difficulty with thinking, problem solving or language (DH 2016). Alzheimer's disease is the most common cause of dementia, accounting for approximately 62% of people living with dementia (Alzheimer's Society, 2014a). Other causes include vascular dementia, dementia with Lewy bodies, mixed dementia and frontotemporal dementia (DH, 2016).

There are approximately 850,000 diagnosed cases of dementia across the UK. By 2025, this figure is expected to reach over one million (Alzheimer's Society, 2014). The financial implications related to dementia care are estimated to cost the UK £26.3 billion a year (Alzheimer's Society, 2014). Though just 1.3% of the UK population suffer from some form of dementia (Alzheimer's Research UK, 2016) the cost of dementia care surpasses that of heart disease, stroke and cancer care. The Government have recognised the gravity of the growing dementia crisis, outlining various strategies and plans to aid the situation though the effectiveness of these are yet to be fully determined (DH, 2015).

This paper considers the challenges posed by dementia and provides a critical review of the literature as to whether nurses are effectively trained to appropriately manage the care of people with dementia alongside the developments for improving education and training.

Methodology

The methodology utilised was a critical review as it provides the flexibility to identify how something is socially understood; a characteristic the rigidity of a systematic review fails to fully account for (Jesson et al, 2011). This method provides the opportunity to use a collection of different material throughout the review; policy and theory, eventually illustrating how an issue has been conceptualised and understood (Edgley et al., 2014).

Dementia challenges

Dementia is a multifaceted condition and effects individuals differently and due to the progressive nature of dementia: communication is one of the areas that can produce the most difficulties (Alzheimer's Association, 2016). Individuals with dementia gradually lose their ability to retrieve and use words to arrange, express and comprehend verbal and non-verbal ideas (Andresen, 1995). They may find it increasingly difficult to understand instructions, sustain conversation or even finish sentences (McIntosh and Woodall, 1995).

Subsequently, people with dementia may struggle with expressing and understanding their care needs, as their condition deteriorates. Early diagnosis of dementia initiates the process of care and treatment planning. This allows the individual to autonomously make informed and important choices about their future; whilst they still have the capacity to do so (Social Care Institute for Excellence, 2016).

Cantley (2001) asserts that the rapidly increasing incidences of dementia are not the only challenge posed to health and social care services. The functional and physiological changes associated with dementia; often coupled with pre-existing co-morbidities, can make dementia care more complex (Bowers and Downs, 2014). It is the presence of such complex care needs which necessitate the input of numerous professions and organisations (Cantley, 2001).

The involvement of different services and disciplines has the potential to cause lapses in care if there is a lack of effective coordination (NHS England, 2014). People with dementia are at an increased risk of medical errors and care inefficiencies during transitions of care. This is a time at which services should be working cooperatively, however, failures in care coordination have contributed to transitional glitches (Tan et al., 2014).

There is an urgent need for care providers to work together to ensure the quality of dementia care is regularly monitored so people have a good care experience (Care Quality Commission, 2014). Nurses therefore need appropriate training in relation to dementia care. Education and training for staff has been identified as the second most frequently used approach in healthcare settings to facilitate improvements in dementia care (RCN, 2011).

There is difficulty in staff accessing dementia training and education which creates a barrier to delivering better care (RCN, 2011) and despite staff receiving training, people living with dementia does not always improve (CQC, 2014, Surr, 2015). In the National Audit of Dementia in 2011, more than half the nurses in acute hospital settings perceived their training on dementia care to be insufficient (Gandesha et al., 2012) however, recent advances and Government policy have been implemented to improve education and training for all health and social care staff.
Education and training.

In 2011, Scotland introduced the Dementia Champions programme. The agenda supported the development of nurses as agents of change in improving outcomes; both in hospitals and at the border between the hospital and the community (NHS Education for Scotland, 2014). Developing nurses' knowledge and competence facilitated their ability to meet the needs of people with dementia and become a dedicated point of reference for other staff members on the ward (Waugh et al., 2011).

Mayrhofer et al. (2016) suggest that the majority of dementia champions believe the education and training they acquired was adequate for their role however, 9% of dementia champions stated they received no training at all. There is a significant relationship between the clinical areas dementia champions worked in and their perception of adequate training. Staff in acute settings were reported to deem their training as inadequate compared to staff in community settings who felt they had received adequate training (Mayrhofer et al., 2016). Though these figures specifically refer to dementia champions, they could be indicative of the perceptions of non-dementia specific nurses.

Ward and Dobson (2014) suggest that the role of the dementia champions has had little influence on the improvement on care. They recommend that training programmes on dementia care should adopt an approach that seeks to understand all aspects of a person; as participants in the study responded positively about the use of this method (Ward and Dobson, 2014).

The National Dementia Strategy (DH 2009) aimed to provide a system by which all people with dementia are able to live well. It identifies 17 recommendations which local services could use as a framework to improve the provision of dementia care over a five year period (DH, 2009). Through this strategy, the government aimed to completely transform the multidisciplinary approach to dementia care (Alzheimer's Society, 2016).

One of the recommendations refers to ensuring that the workforce providing care for people with dementia is informed and effective. The government advise that this is accomplished through the delivery of efficient basic training, as well as on-going professional development in dementia care (DH, 2009). The proposals for effectively training staff on dementia care suggest that education should centre on subjects such as; communication, person centred assessments, nutrition and hydration, continence, rehabilitation, social activity/interaction and end of life care (RCN, 2013).

Following the National Dementia Strategy (DH 2009), the likelihood of successfully developing an informed and effective workforce by 2014 was weak to moderate. In 2015, the Dementia Core Skills Education and Training Framework was commissioned and funded by the Department of Health and developed by Skills for Health and Health Education England (HEE) in partnership with Skills for Care. This framework supports the development and delivery of appropriate and consistent dementia education and training for the health and care workforce. Three tiers of education are described: tier 1 - dementia awareness for all working in health and social care settings; tier 2 – basic skills for those who have regular contact with people living with dementia; tier 3 - enhanced knowledge, skills and attitudes for expert staff e.g. Admiral nurses: designed to support leadership roles.

Latest figures show that HEE have delivered tier 1 and 2 training to 515,967 NHS staff (DH 2016). Given a third of all hospital beds are occupied by a person with cognitive impairment and 80% of people in care homes are cognitively impaired; nurses are highly likely to care for people with cognitive impairment on a regular basis however, the majority of training is at foundation level, indicating a need for an increased emphasis on tier 2 and 3 levels of training (Alzheimer's Society, 2016). The recent briefing from the Council of Deans (2016) on the development of the standards for graduate registered nurses points to dementia care as a key focus.

Evidence has shown that training on dementia, at undergraduate level in the UK, is described as inconsistent and inadequate (Blakemore, 2014). The Higher Education for Dementia Network indicated that coverage of dementia on health and social care courses, at most UK universities was inadequate and inconsistent (Blakemore, 2014). Scerri and Scerri (2013) suggested that the knowledge and attitudes of student nurses towards people with dementia could be enhanced by improving dementia care training and developing their clinical experience.

Skills for Care, Skills for Health, Dementia UK and the Alzheimer's Society, are just a few of the organisations which provide nurses with education and training on dementia. They all set out various frameworks which underpin the fundamental aspects of dementia care which are then incorporated into training (RCN, 2013). One example is the Curriculum for UK Dementia Education, which is a framework introduced by the Higher Education for Dementia Network.

This framework assists higher education institutions with the formation of courses which deliver teaching on the care needs of people living with dementia to health and social care staff (Dementia UK, 2015). This curriculum informs courses at various levels hence the framework can offer support at a pre-registration stage as well as at a post-qualification stage (Dementia UK, 2015). The ultimate purpose of such programmes are to provide participants with the knowledge and understanding to effectively care for people living with dementia.

Spencer et al.'s (2014) results indicated a positive correlation between additional education and practical training and staff confidence when dealing with people with dementia and delirium. Staff reported that the increase in their confidence meant they felt more competent to deliver care to people with cognitive impairments.

By developing a method through which trainees can evaluate their confidence following a training programme, individuals can will gain an early indication of whether their delivery of care for people with dementia is likely to improve, based on their perceived confidence. This is further supported by the CQC (2014) who suggest that the most effective training involves a practical element and allocates time for staff to reflect. However, there is a significant lack of evidence regarding which strategies and methods employed on dementia training programmes, are actually proven to be most effective (Surr, 2015).

Professor Surr and her team are currently working on an evaluation of in regards to dementia education as HEE want to understand 'What works?'. Existing evidence on training and education in dementia has been collated and is due to be published later this year and it is anticipated the work will help identify the programmes and approaches that provide the best outcomes for people with dementia and their families.

Conclusion

The National Dementia Strategy and the Prime Minister's Challenge on Dementia provides a framework to help local services improve the quality of dementia services. One of the aims of the strategy is to raise awareness and understanding through education and training (DH, 2016). There has been advances over recent years to improve awareness and understanding of dementia but further work needs to be done.

This paper has highlighted a gap between education and training and the quality of the care delivered to people with dementia with staff expressing concern regarding the inadequacy of training around the assessment of cognitive ability and management of challenging behaviour. Dementia is a diverse condition, therefore the training should reflect that so staff can feel confident in their ability to meet the holistic needs of people living with dementia.

The literature examined has indicated positive steps towards improving dementia care e.g. the National Dementia Strategy, the Prime Minister's Challenge on Dementia and Making a Difference in Dementia. However, the overarching picture suggests that the nursing workforce is still not sufficiently prepared to manage dementia care as effectively as it could. Research indicates the need to establish the best way to meet dementia care needs as well as ensuring that nurses at pre and post registration level are better equipped for the challenges of dementia (Surr, 2015).

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What are people with dementia and their carers' perceptions of the quality of care they receive in hospitals in the UK?

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Abstract

Title: What are people with dementia and their carers' perceptions of the quality of care they receive in hospitals in the UK?

Aim: To establish the views of people with dementia and their carers who are in receipt of secondary nursing care as opposed to health workers views only. This literature review aims to explore what perceptions patients with dementia have about the health care system and their views of poor and good care.

Background: The Prime Minister's Challenge on Dementia (DoH, 2016) has brought dementia care under scrutiny. Incidences such as the Mid-Staffordshire crisis, has brought to the public's attention the failings within the National Health Service (NHS) in regards to delivering best quality patient care. The prevalence of dementia world-wide has risen and will continue to do so impacting our NHS and demanding higher priority within our hospitals. It has been suggested by the Alzheimer's Society (2016a) that over 30% of hospital beds are occupied by people with dementia. It was therefore determined important by the researcher that the perceptions of people with dementia and their families be explored.

Method: An integrative literature review was conducted. Using a systemic search of the Cinahl libraries, 10 articles were selected and critically analysed implementing the appropriate CASP tools. All 10 articles are of qualitative study design. Once common themes had been identified, the PARHIS framework was used to recognise recent evidence, cultural barriers and facilitation to change.

Results: The results of this literature review found that patients with dementia, their caregivers and nursing staff felt that knowledge was insufficient in regards to dementia. It was also found that patients and caregivers were unhappy with treatment received in hospital care settings due to inadequate communication between health professionals and multi-disciplinary teams.

Conclusion: The author recommends that a Dementia Champion should be appointed to the hospital wards. The Dementia Champion would be a source of information, knowledge and support to the nursing staff, family caregivers and to the people with dementia. Through implementing this suggested change, it is hoped that this will improve the experience of people with dementia and their caregivers when in receipt of nursing care within the hospital.

Introduction

The World Health Organisation (WHO) and Alzheimer's Disease International, jointly developed a report entitled 'Dementia: a public health priority' (WHO, 2012). This offers current statistics of people living with dementia worldwide as an estimated 35.6 million, a figure that will double by 2030 (WHO, 2016). There are also currently an estimated 27 million living undiagnosed with dementia worldwide (Hughes, 2011). The rising prevalence of dementia within the UK equates to 1 in every 14 people in the population aged 65 years and over (Alzheimer's Society, 2014). Hence hospital admission of people with dementia has also risen, and the need for multi-disciplinary team work more important (Sheehan, 2016). Sheehan (2016) states there is little evidence about the perceptions of the people with dementia in terms of their nursing care received. Francis (2013) highlights how poor planning led to people with dementia being discharged in the middle of the night without communication with the carer, leading to feelings of frustration and poor psychological well-being (Mockford, 2015). Greengross (2011) highlights that nursing staff also have feelings of frustration, loss and inadequacy when trying to deliver best quality of care to people with dementia, with many reporting lack of understanding and knowledge in this area.

The Prime Minister's Challenge on Dementia 2020 (PMCD) (DOH,2016) highlights how by 2020 England shall be the pioneer of dementia care, awareness, risk reduction and research, yet with just 5 years to achieve this remaining, Fowler et al (2013) highlights the lack of evidence-based research focusing primarily on the perceptions of the person with dementia. RCN (2013) emphasise that people with dementia need more time and support when admitted to hospital, yet nursing staff have insurmountable time constraints, suggesting this view is unrealistic. The NMC Code of Conduct (2015) state that nurses should stay up-to-date with available evidence to deliver best quality of care to patients, yet the Alzheimer's Society (2016, b) highlight

how, when faced with challenging behaviours, nursing staff misinterpret the reasons behind the presenting behaviours, indicating that training is lacking.

Johns Campaign (2015) encouraged a change within the health care system. The campaign highlights how encouraging carers to stay with the person during their admission, maintains an air of familiarity. Botek (2016) reinforces this view, stating that familiarity helps to calm the patient therefore they become more compliant to medical care. It has been suggested that communication is a barrier for the person with dementia (Alzheimer's Society, 2016b) as some may have difficulty communicating past medical history, psychological and physiological needs. Caswell et al (2015) conducted a qualitative study based on the communication between health professionals and carers. The findings indicated that open communication between health professionals and carers resulted in improved hospital experience for the patient as shared perceptions and outcomes were discussed mutually.

Based on background reading for dementia, the researcher's question was formulated to incorporate a holistic view of care being delivered to and received by the person with dementia, their carers and the nursing staff. It was considered important that all aspects be viewed particularly as due to ethical issues there are limited studies available with just people with dementias' perspectives (Alzheimer's Society, 2016b).

Method

An integrative review is a procedure used to integrate research articles into one condensed review (Souza, et al 2010), allowing the reader to access a wide range of studies without the need to critically analyse and search for them; this is important as new research is published daily but the literature review points out flaws in the presented studies and highlights gaps in missing evidence (Aveyard, 2014). To formulate a question relevant to the chosen topic the tool PICO was used (Jacobs, 2008), allowing the researcher to formulate a specific and measurable question. Due to the nature of the question, qualitative studies were chosen. These are designed to seek answers to questions where answers cannot be predicted, seeking to understand the phenomenological and ethnographic factors as well as beliefs (Mack et al, 2005).

To ensure the articles chosen for the literature review were credible, a search was conducted using Boolean operators, from there the search engines Cinahl, Medline and Psych Info were utilised, giving a broad range of articles to choose from. Non-westernised countries were excluded as their health care systems are potentially quite different to European models. Also excluded were articles dated beyond 2005 as at the time of the search this was within a 10-year frame ensuring the articles were still relevant and in date. The words 'Dementia', 'perceptions', 'nursing care' and 'qualitative' were used, producing 61 search results. By applying a 10-year time frame from 2005–2015, this reduced search results to 44. By adding another phrase to the search: 'carers or caregivers or family members' reduced further to 24 results. Using a systemic approach, the researcher narrowed down the articles to 14 to which the Critical Appraisal Skills Programmes (CASP) tool was incorporated to ensure each article answered the original question.

CASP are used to assess the validity, relevance and credibility of published research emphasising the strengths and weaknesses of the articles allowing the researcher of the literature review to use only the strongest research and disregard the weaker studies (CASP, 2016). Using the CASP tool relevant for qualitative reviews, the researcher disregarded 4 articles due to lack of credibility and not answering the original question, which left 10 relevant articles that had passed the CASP tool criteria.

Exclusion Criteria

Exclusion criteria included: studies published pre 2005; Non-English language studies; studies incomplete; studies that did not use any keywords as previously discussed; studies that did not include a method section as this would not have fit the CASP tool criteria; previous literature reviews as this would not have allowed the researcher to critically analyse the study, deeming it acceptable for the purpose of this literature review; and non- westernised countries as these may have a different approach to health care.

Inclusion Criteria

Inclusion criteria included: studies published between 2005-2015; Westernised countries, as health care within these countries mimics the same health care approach to that of the UK; studies that had the key search words as previously discussed; complete studies; studies that passed the CASP tool criteria; English language studies; and qualitative studies.

Data Extraction Table

Reference	Methodology	Main Findings
Train et al (2004)	Qualitative, Phenomenology design	Staff training found to be lacking. Staff did not have enough experience and knowledge when dealing with behavioural difficulties.
Griffiths et al (2013)	Qualitative, Ethnographic design	Medical professionals found they lacked sufficient knowledge regarding dementia consequently felt could not deliver best care to the patients.
		Managers were unaware of training available to their staff to enhance their knowledge.
Cowdell F (2010)	Qualitative, Ethnographic design	People with dementia and their families found staff taking care of them to lack sufficient knowledge and felt a loss of identity. Staff found training provided to be lacking when faced with behavioural difficulties.
Jurgens et al (2012)	Qualitative, Phenomenology design	The main findings of this study show that carers are dissatisfied with the care their relative/friend had received during their stay within the hospital.
Porock et al (2013)	Qualitative, Phenomenology design	The hospital routine coupled with the noisy environment was distressing to the people with dementia.
Spencer et al (2013)	Qualitative, Phenomenology design	The study found the lack of stimulating activities contributed to behavioural difficulties from the person with dementia within the hospital setting. Staff found they lacked sufficient knowledge to deliver best care to the persons with dementia.
Clissett et al (2013)	Qualitative, Ethnographic design	A lack of person centred care was found within the study leading to persons with dementia feeling a loss of personhood.
Mawaka, T (2012)	Qualitative, Phenomenology design	The study recognises a clear gap between knowledge about dementia and the skills required to deliver best care to those patients. It also recognises that dementia care training is limited within organisations and some staff have been recruited regardless of receiving any dementia awareness training prior.
Digby and Bloomer (2012)	Qualitative, Phenomenology design	Environmental factors contributed to behavioural difficulties with persons with dementia. It was also identified more research is needed within this area.

Results

There were 3 main themes identified through the use of the qualitative CASP tool, data extraction table and the use of the theme table.

Themes identified were:

1. Lack of staff training;
2. Lack of communication between people with dementia, carers and nursing staff;
3. Environmental factors.

The themes presented have been identified to answer the original question and have been selected through recurrent topics within each article (Sally, 2013). Lack of staff training was considered important as this greatly impacts on the care delivered to people (Curr et al, 2016). Lack of communication was also identified as a running theme, the importance of which is well documented within the NMC Code of Conduct 2015. Environmental factors were also recognised as important within the study as homelier environments resulted in people with dementia feeling more at ease (SIGN, 2008).

Results Theme 1 – Lack of staff training

The 'PMCD 2020' states that all health staff shall receive dementia training before 2020 (DOH, 2016). In response to this, Health Education England (2016) released a mandate aimed at ensuring dementia training become more available to health care workers and anyone who has contact with people with dementia. Seven articles highlighted the need for further staff training in regards to dementia care.

In a study conducted by Train et al (2005) entitled *'A qualitative study of the views of residents with dementia, their relatives and staff about work practice in long term care settings'* describes insufficient staff knowledge and training in regards to dementia care within the hospital. However, there were conflicting opinions between managers and nurses within the hospital feeling that dementia training was readily available for all staff; yet, a nurse was quoted as stating: 'No training here. You educate yourself.' WHO, (2016) emphasise how lack of understanding and education in dementia is detrimental to the patient, both physiological and psychological. Without acting upon best available evidence, the nursing staff are in breach of their code of conduct (NMC 2015). A weakness of the study would be that the only areas observed were London and Essex, it also does not specify how many hospitals were included. Another limitation of the study is small sample size, which only included two care assistants/nurses, one manager, two family carers and two patients. Shenton (2004) comments that if a study is small, results are not transferable as they cannot demonstrate applicability to the wider population. However, Nastasi, (2016) argues that even with a small sample size, qualitative research is flexible and can be incorporated to the wider population as the research focuses on a specific group of individuals, events or processes.

'Preparation to care for confused older patients in general hospitals: a study of UK health professionals' conducted by Griffiths et al (2013) had similar findings within their study focusing upon the perceptions of health professionals regarding the lack of educational training about dementia and complex needs. Griffiths et al (2013) discovered that ward managers were unaware of training courses available to enrol their staff on to assist with dementia care. As a result, it was recorded that staff were reporting low morale as well as emotional stress and lack of psychological well-being. Details of how participants were selected were not given. This creates a biased view as without understanding how participants were selected creates questions relating to whether the researcher only recruited participants willing to support their own hypothesis (Collier and Mahoney, 1996). Data extraction was undertaken using a Consensual Qualitative Research approach. Hill, et al (2005) recommend this method of data extraction as this means multiple judges are used throughout to foster a multitude of perspectives which eliminates bias from the results. An independent auditor will then oversee the findings of the judges, ensuring work is correct. For this to be achievable, all judges within the team should be able to vocalise their own opinions otherwise themes could go unnoticed (Elliot and Timulak, 2005). Another potential for bias was that the majority of participants were of ethnic origin of white British (Aveyard, 2014). The results reveal a lack of educational training for all health care staff, confirming Department of Health's recommendations for the further development of training (2009).

'Care of older people with dementia in an acute hospital setting' conducted by Cowdell (2010) found that care givers and people with dementias' perception of the care received was inadequate and that nurses were inexperienced, leaving the patients with feelings of insecurity. The study was of an ethnographic design and utilised Katz 2011 three stage 'what', 'how' and 'why' model to interpret and describe events experienced. An acknowledged limitation of this study was that the behaviours observed could have been enhanced during the observational period (Mcleod, 2015). However, this would not have had sufficient influence during the semi-structured interview stage, so results would not be impaired by this outcome. The findings reinforce the importance of more education for nursing staff as they will have the most one-to-one contact with the patients during their hospital stay, reinforcing the findings from Train et al (2005) and Griffiths et al (2013). However, Porock et al (2013) authors of *'Disruption, control and coping: responses of and to the person with dementia in hospital'* added that although more education is important to enhance the care given, education should also be sourced from the carers as they will have a higher level of understanding about the behaviours and structural routine of their patients, reinforcing the need for more education for health care staff but from a different aspect of learning. A limitation of this study was that co-patients who were interviewed became reluctant to continue with the study, withdrawing consent. Gabriel (2011) highlights this as impairing the overall results, but for the purposes of the original question, only the perceptions of the people with dementia and carers were acknowledged. Due to the illness of some of the patients who were admitted into the hospital, communication became an issue; to overcome this barrier, the researcher used Kitwood's model of personhood to understand the actions and views of the patient (Alzheimer Europe, 2016). Despite this, the method is open to interpretations, thereby impairing the over-all result of the study (McDonagh, et al 2013).

Spencer et al's (2013) study *'Delivering dementia care differently-evaluating the differences and similarities between specialist medical and mental health unit and standard acute care wards: a qualitative study of family carers'* perceptions of quality of care' compared the hospital experience to that of a mental health unit. It became apparent that hospital staff were less equipped to care for patients suffering with dementia compared to that of the mental health unit. Spencer et al (2013) state that due to lack of understanding

and limited training, this contributed to the breakdown of communication between the family and staff, leading to further confrontations. This supports the findings from Porok et al (2013) that education is not just to be sourced from management training but also from the carers of the people with dementia, allowing further insight into what symptoms the patient presents and allowing care to be tailored to meet individual needs (Alzheimer's Society, 2016b).

Potential bias was acknowledged early in the study, however there was a lack of information regarding the researcher's role. Fink (2000) comments that without acknowledgment from the researcher, personal beliefs and views could influence the results. Clissett et al (2013) published *'The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families'* studying the challenges of achieving person-centred care in acute hospitals in a study which examined the perceptions of the person with dementia, their carers', and also co-patients. 29 patients with cognitive impairment were identified all aged over 70 years. However, although the patients were identified and observed on the wards, this researcher did not conduct the interviews until the patient was discharged. This can lead to distorted views of their stay within the hospital; giving time for reflection can make small incidents that were deemed unimportant at the time of the interview, manifest themselves into larger problems (Hancock,et al 2009). The results of the semi-structured interview were recorded and transcribed verbatim to ensure all the research was explored. 52% of the participants were female with a mean age of 88 years. 28 carers also participated with a mean age of 60 years. Only two researchers conducted interviews within the patients' homes, and when interviewing the carer, the participant with dementia was also present, which could influence the views and honesty of the carer (Maxwell, 2008). In comparison with the previous studies, this focuses more on the perceptions of the people with dementia and that of their carers, giving further insight how nursing care is perceived. It also supports previous evidence regarding lack of staff training within the wards. Although this study does not reflect the opinions or views of the staff delivering care to the patient, the third-party perspective is from the view of the carer, giving valuable insight into their interpretation of nursing actions (Eyden, 2011).

'Audit in improving dementia care on the inpatient wards' published by Mawaka, (2012) conducted an audit study highlighting areas of improvement from the perceptions of the nursing staff. This study supports the overall findings of the previous studies mentioned. The published article only includes a small section of the overall study conducted, therefore the results cannot be taken at face value as the focus group section and the documentary analysis are absent. Without sufficient data the representativeness of the results cannot be gauged (Johnson, 2016). 90 questionnaires were distributed amongst nurses from the ward manager; less than half were completed resulting in a smaller scale study. Small scale studies, although common with qualitative studies, does limit the ability to apply the results generically (Anderson and Postlethwaite, 2007). Although evincing no new evidence this study does support previous findings that staff are undertrained and not confident when caring for people with dementia.

Theme 1 has highlighted the importance of educational training for nurses within the hospital. All the studies found this, but do explore different aspects of training; both formal training or learning from the patients' caregivers.

Theme 2 Lack of communication between nursing staff, carers' and people with dementia.

The NMC Code of Conduct (2015) emphasises the importance of effective communication. However, a common theme found within five articles was the lack of communication between nurses, patients and carers, resulting in the breach of that code, which left families and patients feeling vulnerable and confused (Stokes, 2013). Cowdell's (2010) ethnographic approach, identified a common theme in the lack of communication between the patients and nurses. During 125 hours of observations, the researcher witnessed occasions where patients became frustrated when not listened to and most felt they were largely ignored by the nurses; however, staff considered they were treating their patients the way they wished their own family to be treated. The researchers concluded that although Kitwood's personhood was being utilised, the nurses were concerned with the physiological needs rather than holistic needs (Dewing, 2008).

Jurgens et al (2012) conducted a phenomenological qualitative study entitled *'Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study'* to discover the reasons behind older people with dementias' dissatisfaction regarding hospitals. They indicate a lack of communication between nurses and patients, and between nurses and caregivers. Carers felt nurses evaded questions or did not communicate changes regarding care, ward transfers and discharges. Leaving them with feelings of loss of control, confusion, frustration and anger. A limitation of this study is the lack of sufficient information being provided about the methodology. Although the study identifies views of people with dementia, it also includes other cognitive disorders such as delirium which can impair the results as it is not exclusive to dementia (Hancock, et al 2009). Another limitation is that it does not specify the participant selection process. 250 patients were approached but it does not explain how only 35 took part. According to Sargeant (2012) this impairs the results as details regarding the inclusion and exclusion should be presented in order to prove bias was eliminated from the study. In comparison with Cowdells (2010) this reinforces the view that communication is lacking, but in Cowdell's (2010) study, views of people with dementia were explored

more fully whereas Jurgens (2012) only explores views from the carers perspective.

Porock et al (2013) reinforces these findings. During 72 hours of observations from two hospitals within the East Midlands region, they highlighted how valuable communication was to the person with dementia and their carers. When patients were disturbed without explanation they became less compliant. Porock et al (2013) also comments that due to poor communication between nurses and family carers, disputes and confrontations became more frequent. A limitation to this study is a lack of information supplied regarding the topic guide for the semi-structured interviews, leaving the reader unable to understand how responses were formulated (Maxwell, 2008). Porock et al (2013) reinforces the findings of poor communication.

Spencer et al's (2013) study also concluded that within the hospital communication was key and found that within the specialised mental health units this was not an issue that arose. They found that within the mental health units, extra training is provided to staff in regards to dementia care, resulting in staff who are more comfortable communicating with the patients and their carers'. Yet within the general hospital, the nurses found it difficult to communicate, revealing lack of understanding regarding the patients' holistic needs. Although the limitation of this study is the small sample size, it does reinforce views found within previous studies, that communication is lacking within hospitals (Fink, 2000). For example, Clisset et al (2013) found that nurses failed to make personal connections with patients.

Larsson (2011) conducted a qualitative study entitled *'Patients' Perceptions of Nurses' Behaviour That Influence Patient Participation in Nursing Care: A Critical Incident Study'* to further understand the perceptions of patients when a personal connection between patient and nurse is absent. The results revealed that when a personal connection has been created, the patient feels valued as a unique person and is more likely to be compliant with medical care. For this to occur, communication is essential, giving greater insight into the person with dementias' basic human needs resulting in the nurses having a greater understanding of their patient (Alzheimer's Society, 2016b). This reflected Clisset et al's (2013) findings that communication is not just essential for nursing care of the person with dementia but also so they feel they are not a burden upon the nurses.

The main findings from these studies reveal that communication is essential when caring for people with dementia and their carers. Studies have explored different aspects of communication both from the perceptions of people with dementia and also the importance of nurses communicating with the caregiver. Carers see communication with the nurses as essential both to enhance the quality of care provided to the person with dementia and to ensure they are also kept up-to-date with the care; carers feel they should be communicating with nurses as they have valuable insight into the behaviours, routines and personalities of the person with dementia.

Theme 3 Environmental factors

Another common theme is the environmental factor contributing to the hospital experience of the people with dementia and their carer. Pool (2010) explored the importance of a calming environment for the patients, which can help the patient to feel more relaxed and less stressed with the transition from home to hospital. This view is reinforced by the Alzheimer's Society (2016) who state that the busy hospital ward creates increased confusion for people with dementia leading to exacerbated behavioural challenges. However, only two studies found this as a common theme.

Digby and Bloomer (2012) published *'People with dementia and the hospital environment: the view of patients and family carers'* and found that behavioural issues became exacerbated due to a change of environment. Nevertheless, upon interviewing the patients it was found that they cared more about the care they received from the nurses rather than the environment. Ethical considerations were taken into account and the local ethical committee were approached prior to sourcing participants, however once consent was gained either from the participant or the next of kin, it became apparent some of the people with dementia could not give a deep insight, limiting the study's results (Al-Busaidi, 2008). Triangulation was used to support the findings in order to determine its credibility; that is the implementation of multiple methods and data sources to understand the phenomena of the results (Carter et al 2014).

In comparison Zadelhoff et al (2011) who published *'Good care in group home living for people with dementia. Experiences of residents, family and nursing staff'* found that people with dementia valued a sense of homeliness above that of the care they received. Carers and patients reported feelings of security and safety within the environment which they felt were important in order to minimise challenging behaviour. However, this study was conducted within a small group home therefore does not represent the hospital setting. Yet for the purpose of this literature review, it was deemed important as it gave deeper insight into the perceptions of the people with dementias' long term care. It was also revealed that some of the people with dementia could not give deeper insight into their perception (Al-Busaidi, 2008) therefore, participants' facial expressions during interviews was noted to support the interviewer's perceptions of what the participant was trying to express. The study also has a ratio of 9 females to 1 male which would give biased results as this does not represent the wider population (Hoets, 2012). In both studies the environment was deemed an important element as literature supports the need to provide a calming environment for the patient in order to minimise

exacerbations of challenging behaviour and to help the patient feel safe and secure within the hospital (SIGN, 2008).

Conclusion and Recommendations

In conclusion, the literature review indicated that further education for nurses is required within the hospitals. Train et al (2004) concluded patients and carers were left with feelings of frustration, loss of control and lack of person-centred care due to nurses not understanding the patients' conditions.

The author considers that in order to promote better care a dementia champion programme should be implemented within the hospitals (Scottish Government, 2010; Department of Health, 2009). A study was conducted seeking the views of people with dementias about implementing Champion Dementia nurses into the hospitals, revealing that 85% of the participants agreed with the results of this review and felt that support within the acute setting needed to be improved (Bank et al, 2014).

The role of the Champion Nurse is to improve nurses' knowledge, awareness and health care needs of the person with dementia and to educate patients themselves and their caregiver (Mayrhofer et al, 2016). This is vital as carers have reported feelings of loss, frustration and lack of understanding when trying to care for their loved one (Alzheimer's Society, 2007). In contrast to this, education for carers can be viewed as demeaning, resulting in some carers disregarding the advice given, viewing it as 'unwanted' (Atreja, 2005). When a person with dementia is admitted to the hospital, it has been proven the comorbidity of the patient becomes more complex thus altering their needs upon discharge (Scrutton and Brancati, 2016). Lack of adherence and compliance with educational advice could consequently result in detrimental consequences (Cornwell et al, 2012).

Evidence suggests that educating nurses to a higher standard in regards to dementia care would be both beneficial to the person with dementia and the nurses delivering care (Mayrhofer et al, 2016).

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A well written appropriately constructed paper makes the editors' job simpler and hastens publication. To this end the following should be considered, but where doubts remain enquires, prior to submission, as to suitability, styles etc., can be sent to the editors.

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Sheldon JH. (1948) *The Social Medicine of Old Age: Report of an inquiry in Wolverhampton*. Oxford. Oxford University Press.

Chapters in books
Mountain G. (2010) *Assessment and dementia* In Downs M and Bowers B (eds) Excellence in Dementia Care Research into Practice. Berkshire. Open University Press.

Journal references
The authors' names are followed by the title of the article; year of publication: the title of the journal either in full or abbreviated according to the style of Index Medicus (in italics); the volume number; the issue number if applicable; and the first and last page numbers.

Holmes C., Hopkins V., Hensford C., MacLaughlin V., Wilkinson D., Rosenvinge H. (2002) Lavender oil as a treatment for agitated behaviour in severe dementia: a placebo controlled study. *Int J Geriatr Psychiatry.* 17: 305-308

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British Geriatric Society. (2012) Population and Projections. Available at: http://www.bgs.org.uk/index.php [accessed on 3 /3/12]

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The Journal of the Institute of Ageing & Health (West Midlands)

Ageing and Health is a peer reviewed journal aimed at people working with and for older people.

The main objective of the journal is to provide a platform for carers, older people, healthcare practitioners, students, academics and researchers to share their experiences and / or research in the field of working with, and for, older people. Ageing and Health aims to promote and share areas of excellent practice that promotes wellbeing for older people.

The journal is currently published in print but aims to move to online in the future.

Ageing and Health publishes original papers, review papers, conceptual frameworks, case studies, empirical research, book reviews, discussion papers, audits/evaluations of services, poems, literature reviews, etc.

We welcome new authors as well as those with experience in publishing.

The author guidelines can be found on our web site at:
http://iah-wmids.org.uk/index.php/documents/category/2-ageing-health-journal

For more information please contact the editors or send your manuscript to the editor at:

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With thanks

Dr Ruth Pearce and Sue Lillyman (Editors)

TRAINING AND EVENTS – SAVE THE DATES!

In order to fulfil our mission of bringing health and social care professionals the most up to date information about issues affecting older people the Trustees invite you to hold the following dates in 2017 in your diary:

Loneliness Seminar and AGM: **Friday 28 July 2017**

Annual Conference: **Friday 17 November 2017**

These events will provide a policy and professional overview of key issues affecting older people and will also have a practical element incorporated into the session so you can think about how to take the learning back into your workplace.