

PROJECT REFERENCE 109/124

FINAL REPORT

End of Life care between home, nursing homes and district hospitals: A Nurse led action research project examining patient pathways from home or nursing homes via A& E wards.



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Project references 109/124

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End of Life care between home, nursing homes and district hospitals: A Nurse led action research project examining patient pathway from home or nursing homes via A&E wards.

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Project Summary

End of Life care between home, nursing homes and district hospitals: A Nurse led action research project examining patient pathway from home or nursing homes via A&E wards.

This nurse led action research interviewed 22 bereaved relatives and 17 key health and social care professionals to examine the patient pathway of patients admitted via accident and emergency during the last 48 hours of life. All patients had long term conditions such that end of life was not unexpected.

The study identified and examined the critical junctures and care decision making along the patient journey in order to patient care at the end of life.

Between 2005-2006 consultant clinicians identified that **70** patients admitted to the local hospital required end of life care which could have been provided elsewhere – for example in a hospice, nursing home or at home with nursing support.

Findings

53 % of patients were admitted from nursing or residential homes. The majority of patients were admitted from the most deprived areas of the locality. 62 (88.5%) patients were admitted as an emergency, via a 999 call, and presented via the Accident and Emergency department where they were reviewed prior to admission. Once admitted, 26 (37%) were moved at least 3 times during the last 48 hours of their life.

Errors in coding, consultant and location of patients were identified during the clinical review. Procedural and policy changes were made within the hospital as a direct result of the study findings.

Interviews with relatives and key informants identified issues relating to the hospital environment, staff numbers and resources. The unpredictability of death was an important issue and meant that relatives were often unaware of how imminent death was. Some relatives suggested that if they had known this it would have affected the decisions they made in relation to transfer, and leaving their relative.

Care following death was important and was sometimes given a lower priority by hospital staff because of other service demands.

Competences, skills, policy and protocols within private, council and NHS organizations played a major role in decision making and were a key trigger for transfer to hospital,

Communication between patients, family members and health professionals was a critical area raised by both relatives and key informants. Failure to communicate well led to a variety of negative emotions which remained powerful over twelve months later.

Many of the decisions made at critical junctures along the pathway occurred as a result of complex interactions such that simple interventions were not always obvious. Decisions to transfer to hospital were much more likely to be as a result of carer exhaustion, lack of support, fear and panic. Knowing that the patient did not have much longer to live may well have prevented this move especially in those interviews where relatives had wanted end of life care at home. These cases were particularly poignant and served to emphasise the lack of support and help available within the community which resulted in the move to hospital and often left the relatives with a sense of failing their relative's last request.

Patient transfers were always by ambulance, if the transfer was via a 999 call, the ambulance crew assessed each individual situation to see if the patient should be transferred to hospital. Advanced life directives were considered but were often not up to date or created in accordance with the ambulance policies and protocols and so could not be used.

Transfer by the emergency ambulance service meant that patients were always admitted via the A&E department. Government targets are that no patient should spend longer than 4 hours in Accident and Emergency and so patients were often moved to the emergency medical unit (EMU) where they stayed until a bed on a ward became available. In such cases this meant that patients and relatives experienced moves three times within their last 48 hours of life.

Whilst there were few criticisms of clinical care during this time and with these moves, relatives reflections focussed more on the quality of care – the disruption associated with moving from place to place, the impact this and the environment had on the personal and private time with their dying relative. Improvements could be made by:

- Identifying a number of palliative care beds within the acute hospital setting,
- increasing the number of single rooms for patients nearing the end of their lives.
- Targeted and specific education in building confidence among Health Care Assistants caring for patients at the end of life – utilising the skills, knowledge and experience of Hospice at Home team.
- The possibility of a flagging system which would allow patients to choose whether to come into hospital or stay at home
- Exploration of bypassing Accident and Emergency and being admitted to the Emergency Medical Unit.

Nursing research

As part of this study activities aimed at building individual and institutional nursing research capacity were undertaken. Two nurses seconded from practice were involved as researched in the study. In addition, work was conducted at the district hospital (Purkis et al 2008) and is in the Appendix. The level of research knowledge, activity and experience of nurses working within the Trust was collected. Workshops were designed as informal drop in type sessions run across four consecutive weeks. Within the hospital trust, the team have been invited to have ongoing involvement in the management training of nurses at the point of qualification.

Follow on Work

As a direct result of this study:

- An applied theatre performance on End of Life Care drawing on the issues from this study and working with staff and students is being developed by Claudette Bryanston (theatre director) and Lewando Hundt. The performance will be called 'Passing On'. And it is hoped will be performed in hospitals, nursing homes and residential homes during 2009-10 as a professional development activity to build capacity in end of life care.
- The hospital chaplain with support from the research team, has developed a funding proposal for developing and piloting a spiritual tool, has been requested He has applied for funding from the Strategic Health Authority.
- The research team is proposing to apply for funding with the Hospital Trust to the National Institute for Health Research, Research for Patient Benefit, to pilot a palliative care pathway at the hospital. This takes forward suggestions by health professionals elicited during this study.
- Presentations in the seminar series of the University of Warwick, at the Strategic Health Authority, End of Life strategy meeting and at Local Trust Board meetings
- Papers accepted at Royal College International Nursing Conference in Harrogate, 16th International Learning Conference on work based learning and the

Conclusion

There is a need for improved communication and paperwork which fits policies and procedures of different organisations and which will allow patients, relatives and professionals to work together to make informed decisions at critical points along the care pathway. This study found that for some relatives, had they been aware of the dying trajectory and been provided with access to swift support, help and advice it is likely that they would have died at home. For others however their preference was to die

in hospital irrespective of the imminence of death or level of support in place. There is therefore a challenge for district hospitals and nursing homes to offer end of life care that is person centred and which allows death with dignity, whilst meeting the needs of relatives within the spatial, clinical and administrative conditions by which staff are constrained.

Health and social care professionals working with the community, private and NHS settings are clear that to do this they need access to training which will help build their confidence, skills and knowledge in providing end of life care to both patients and relatives.

Project references 109/124

Final report

End of Life care between home, nursing homes and district hospitals: A Nurse led action research project examining patient pathway from home or nursing homes via A&E wards.

This study, funded by the Burdett Trust for Nursing from 2005 - 2009 has allowed researchers at the University of Warwick with nurses from George Eliot Hospital, to undertake a three year, nurse led action research study. The study started in October 2005, was granted an extension of six months owing to staff changes and was completed in March 2009. The study aimed to address several critical issues which occurred in end of life care within nursing homes, A&E departments and wards within a district hospital in North Warwickshire. The district does not have a residential hospice but has access to a small day hospice, and to a 41 bedded community care and rehabilitation hospital. The following report presents the key findings at the end of the three year period. It begins with the background and aims of the study, continues with a summary of the main outcomes and finally presents the outcomes of each of the study aims.

Study Team

The study team was nurse- led by Dr Judith Ann Jackson, Associate Professor of Inter-professional learning at Warwick Medical School who worked closely with the Co investigator Professor Gillian Lewando Hundt and Dr Loraine Blaxter. The team met regularly throughout the study. Three research nurses were employed as Research Fellows during the project. During the initial stage of the study Elizabeth Burnham was seconded from the Hospital Trust, during the middle phase, Carol Stockman was seconded from a local Primary Care Trust, and Dr Judith Purkis was employed at the University of Warwick.

The study aims were:

1. To map patient pathways for end of life care from home or nursing homes to A/E and on to admission.

2. To learn from the experiences of bereaved relatives and nursing staff how to improve end of life care.
3. To identify critical junctures of referral and care decision making and to work with key professions and personnel to improve end of life care.
4. To improve the patient care environment for end of life care.
5. To develop nurse led action research that would support nursing research capacity building and leadership.

This study was able to:

- Identify patient pathways and critical junctures where interventions could improve care
- Contribute to identifying the resources needed currently, and in the future, to deliver quality end of life care through knowledge transfer to health professionals and administrators locally and regionally.
- Raise awareness of nursing research within the GEH by embedding sessions within introductory management training for newly qualified nurses and within the preceptor booklet.

Background

Several published studies suggest that patient transfer occurring in the last few days of life, are in part due to lack of intermediate care (Mohammed et al 2002), as a result of relatives requesting transfer (Williams 2003), a reflection of the lack of confidence, training and support within nursing and care home settings (James et al 1993).

These studies also highlight that most patients are admitted as emergencies and therefore enter via the A/E department. Such departments are not equipped or designed for dealing with end of life care in patients for whom palliative, as opposed to emergency care is needed. In 1985 The Department of Health and Social Services circulated guidelines for delivering optimal care to patients dying in A & E. These guidelines primarily drew attention to the immediate needs of relatives following their sudden loss, as well as their needs over subsequent weeks. In 1992 however, a study by Cooke et al, identified that there were still inadequacies in the delivery end of life care within A/E departments situated in large hospitals. The authors went on to produce guidelines to help improve end of life care to the bereaved relatives of patients who die suddenly and often unexpectedly in A/E.

More recently (2008) the Department of Health has published an End of Life strategy (DoH2008) which prioritises patient centred care at the end of life and advocates that both commissioners and providers should use integrated care pathways to ensure quality and continuity of care at the end of life. The findings from this study are therefore timely, as they provide evidence to enable the Hospital Trust and Strategic Health Authority to implement interventions to improve care at the end of life.

Recent figures produced by the West Midlands Accident and Emergency Surveillance centre show that 61% of over 75 years olds arriving by ambulance to A&E are admitted to hospital (Downing A¹). Nearly 2/3 of older adults attending A&E are classified as non-injuries, with highest attendance seen in the evening and night, suggesting that this may reflect a lack of support and resources at the point of referral. In these figures, more than half of this group of patients were admitted to hospital, with 1.3% dying following admission (Downing A²).

A clinical audit undertaken at George Eliot Hospital (GEH) in 2003 by Wood & Ryan, identified that

- 38% of all patient deaths occurring at GEH, could have been offered end of life care in a more appropriate environment (e.g. home, nursing home, hospice)
- 31% of all patient deaths occurred with 48 hours of admission.

During the year Oct 2005 – Oct 2006 the team identified that 292 deaths occurred at the hospital within 48hrs of admission. The findings of our study suggest that of these deaths, approximately *46% required care which could have been given in a more appropriate environment (i.e. at home or in a hospice)*. The findings also supported clinicians' anecdotal evidence that people may be being transferred to the hospital to receive end of life care.

Methods

This was a multi-method study with several different components.

- **A clinical record review was undertaken of 151 records** of adult deaths within 48 hours of admission to hospital (sudden deaths excluded) by two consultants who did not treat the patient.
- Semi-structured **Interviews were conducted with 17 key informants and 22 bereaved relatives** recruited from the record review.

- **Four observational sessions** were carried out in A&E at the George Eliot Hospital.
- **Six group interviews with participatory techniques were conducted with staff** in nursing and residential homes, within the hospital and day hospice in the area and with committees within the Trust. Nursing research capacity was undertaken at both individual and institutional levels and is reported under Study Aim 5.

The clinical record data was analysed using SPSS and some Geographical Information Analysis was conducted to map the coverage of care and patient pathways in the area. The interviews were recorded and transcribed and then analysed using NVIVO7. A collaborative approach to analysis was taken with several team members reading the same interviews and identifying emergent themes separately, and then the research fellow, coding the data within these emergent themes with discussion of any additional ones identified.

Service user involvement and the Advisory Group

The Advisory Group met three times during the study and had representation from the main stakeholders – the district hospital, the Primary Care Trust, other researchers on emergency and end of life care, user representatives recruited from UNTRAP, the university-user teaching and research action partnership.

The three users who had experience as carers and bereaved relatives acted as the expert reference group for the study. In this capacity the users reviewed and commented on the study information sheets and consent forms, and were available to be interviewed so that the topic guides for the interviews could be piloted and the nurse researcher able to hone her interview skills, following training, and prior to undertaking interviews with study participants.

Ethical Permission

Ethics permission was obtained from the North Warwickshire Local Research Ethics Committee.

Study Aim 1: To map patient pathways for end of life care from home or nursing homes to A/E and on to admission.

An initial audit on all deaths occurring within 48 hours of admission was completed by the research nurse (EB), working closely with the coding department and the medical

director for the period October 2005 – October 2006. Demographic data relating to age, postcode, gender, and ethnicity (where available) and type of residence was collected. Background information of source and reason for admission, medical diagnosis and cause(s) of death and patient movement following admission was also recorded.

The research nurse identified and excluded those patients who died suddenly and unexpectedly. The remaining records, belonging to patients who had long term illness and whose death was not unexpected, were sent to one of ten clinical consultants within the Trust. Consultants were asked to review each patient's records with regard to the admission diagnosis, the cause of death and any co morbidities which may have contributed or caused death. Consultants completed a pro-forma confirming whether in their professional opinion, it was in the patient's best interests to be admitted to an acute hospital or whether patient care could have been better met in an alternate setting. Clinicians were also asked to select from a suggested list where such care could have been received.

Over this one year period, 292 deaths occurred within 48 hours of admission. 151 notes were sent to the consultants for review. Consultants identified 70 (46%) patients who could have, in their clinical opinion, received care in an alternative setting to an acute hospital, for example within a hospice setting, or within the patient's current home accommodation with possible support from a hospice at home team or other nursing care through Macmillan/ Marie Curie nurses.

Sample Descriptors

The average age of patients was 80 years (SD 11.6), 39 female, 31 male. 37 (53%) were seen at the Accident and Emergency department before 09.00 or after 19.00, 14 (20%) patients were admitted at the weekend.

The reason for referral to hospital (taken from the patient records), ranged from such general undefined terms as patient was 'unwell', 'poorly', 'had deteriorated' to more specific 'chest pain', 'diarrhoea and vomiting' and 'shortness of breath'. Patients were grouped into 4 categories for analysis, either respiratory, circulatory, cancer or other, dependent on their long term illness and medical diagnosis at admission. Most patients (28) had a cancer diagnosis, 16 circulatory, 17 respiratory diagnosis and 8 other.

Care pathway

Over 50% of patients who could have received care elsewhere were admitted from nursing or residential homes, (Table 1). This is an important finding and indicates that nursing and residential homes are not equipped in terms of staffing or procedures to enable patients to die there.

Table 1: Source of Admission

Admitted from:	
Own Home	45.7% (32/70)
Nursing Home	31.4% (22/70)
Residential Home	21.4% (15/70)
Hospital Transfer	1.4 % (1/70)

46% were admitted from home and this too reflects relatives not having adequate and timely access to nursing and medical support to care for someone at home. GIS mapping using patient postcodes identified that the majority of these patients were living in the most deprived areas of the locality.

62 (88.5%) patients were admitted as an emergency, most usually via a 999 call, and presented via the Accident and Emergency department where they were reviewed prior to admission. 3 (4%) were admitted straight into an emergency assessment unit at the hospital and 5 (7%) were admitted directly to the coronary care unit.

Table 2: Patient Pathway till death (which occurred within 48 hours of admission).

In the last 48 hours of their lives 37% (26/70) patients were moved 3 times.

The most common pathway was:

Accident & Emergency → Emergency Medical Assessment Unit → ward.

Government targets limit patient stay in A&E to 4 hours, within this study sample the mean stay time was 2.73 hrs (range 0-11.98). 52 (74%) patients were then moved to the Emergency Medical Unit, often to wait until a bed was available on a ward. Using this pathway 26 (37%) patients were moved 3 times during the last 48 hours of their lives.

Coding and Administrative errors

- Discrepancies in coding were identified by the nurse researcher. Errors were also found in the recorded and actual source of admission.
- There was an underreporting of admissions referred by their GP to the hospital and there were discrepancies between the time of death recorded in the patient records and that recorded on the hospital system.
- Discrepancies in clinical allocation occurred due to the practice of using incorrectly headed consultant notepaper.
- Detailed examination of patient records and the Patient Administration Service (PAS) system showed that if a bed was not available on the admitting consultants ward, the patient would be allocated to another ward. If this happened the PAS system became an important resource for identifying to the medical teams where their patients were. If the PAS system was not up to date these patients (known as outliers) were likely to wait much longer to see a doctor since the admitting consultant did not routinely visit these wards.

Changes made in clinical practice as a result of study findings:

Changes were made or are ongoing to rectify these issues.

Improvements in coding and record keeping were made.

Consultant headed notepaper was withdrawn, junior doctors were trained on completing *Key Mortality Factor (KMF)* forms, coders joined ward rounds to audit doctors' use of International Statistical Classification of Diseases and Related Health Problems (ICD codes).

The improvements in coding along with some other measures has removed the hospital from being red flagged by Dr Foster's in relation to mortality rates. The findings from this study have on a regular basis been fed back to the Trust via attendance at the monthly mortality meeting, presentations at the Hospital Grand Round and at Dissemination of Audit, Research and Evaluation Meetings. This has helped the Trust and clinicians

identify issues relevant to the mortality rates at the Hospital. There are now at least two and sometimes three senior nurses present at the monthly mortality meetings.

The movement of patients was discussed with consultants who identified difficulties in making changes to this practice. These difficulties related mainly to targets and bed availability. The study team are still involved in ongoing discussion through internal committees and a bid is being prepared to the NIHR Research for Patient Benefit, to obtain funding to pilot the creation of palliative care beds within the hospital, so that admissions of individuals near the end of life will be able to bypass A/E.

Study Aim 2. To learn from the experiences of bereaved relatives and nursing staff how to improve end of life care.

Twenty two bereaved relatives were interviewed as well as seventeen key informants such as chaplains, ambulance service staff, staff in A&E. Most carers of the patients were relatives – usually partners of the deceased but in some cases their children and in one case the mother of the deceased.

Carers were encouraged to tell the story of the end of life care experienced by themselves and their relative. This included the pathway of care, their involvement in decisions as well as the rationale for the decisions made. In this way both the carer's voice and the deceased experiences were captured. The key informant interviews provided a range of perspectives on end of life care from people with different professional backgrounds.

The key informants worked both within primary and secondary care, in statutory and NHS settings. Interviews with chaplains, mortician, porter as well as consultants and nurses within the local hospital, with matrons, ambulance personnel, hospice at home, out of hour's personnel within the community setting and staff in nursing and residential homes were completed.

Key informants offered an insight in to their role as well as participation and their perspective on end of life care. They highlighted both the opportunities and challenges they faced in their professional practice and they offered suggestions for improvements.

Key themes from the interviews with relatives and staff.

(Relatives - R, Staff Key Informant - K)

Hospital Care and Environment

A major theme related to hospital care and the environment. Many relatives felt very positive about the attitudes of staff on the wards;

And every nurse that came on was really helpful and that I can't find any fault with them really. (R11 Husband)

I stayed over night ... every time there was a change of nurses I thought, oh I'm going to get kicked out because I just stayed there you know.... But they didn't ... obviously passing on messages from one set of the staff to the other was absolutely marvellous ... they not only looked after my husband, they looked after me and the children You know... we were looked after as a family (R20 Wife)

However there were also incidents – often small - where care had been perceived as inadequate. This was highlighted by both relatives and staff. There were indications that staff were very busy. This particular district hospital has a very high number of patients per nurse, i.e. it is understaffed in relation to nursing staff.

She was really, really thirsty and we kept asking the nurses if we could have some of those swab things.....and they kept saying yes, we'll bring it, we'll bring it and....it just never ever happenedit just sticks in my mind that (R1 Daughter)

Here's one quite recently, members of staff shouting at a patient who might be shouting out.....you know "SHUT UP"that's, I find that really difficult....., I still go back to that patients charter of rights standard one 'we should treat patients with dignity and respect' (K1 Chaplain)

No, no, no they were too busy You know, quite clearly they were grossly, well I say understaffed (R 22 Carer)

The hospital environment was perceived by both relatives and staff to be less than ideal as a place to die, owing to lack of privacy, partly made worse by the use of paper curtains around beds, to avoid infection.

.She just had the curtains around, the other ladies in thereall had just woken up for breakfast and they were sort of seeing to their needs and.....you're sat behind this curtain and itwasn't very private butyou knowbut no it was nice to...have that time yes (R1Daughter)

The only other problem we have on the ward ... with the new style ...disposable curtains is, is that they don't , they don't cover the beds at all really and ...gaps can appear and obviously patients can see through those gaps (K4 Porter)

We don't have enough side rooms to deal with our isolation needs, let alone... you know, maintaining a sort of a private space for dying patients and their relatives (K5 Matron)

The lack of a quiet private physical environment within the hospital ward was identified by both relatives and staff as a key factor.

There was my dad, 88 year old man...looking dreadful...on oxygenbeing moved. There were visitors everywhere, noise everywhere...Why they had to move my dad from a very, very peaceful area, telling me he only had hours left to live...Pushed into a bay... All squashed in... (R15 Daughter)

I mean its not really the best place to die, its not nice for the other patients in the bay, they can't always find a side room for people to use and the relatives, its not good for the relatives, its not good for the staff, because they know its not the right place for them and its very difficult to provide that sensitive care when there's five other patients in the ward (K1, Chaplain)

Lack of clarity about the actual timing of the last few hours of life

The actual time of death and the process of dying were considered by many to be unpredictable which made it difficult to ensure that adequate resources and support were available. Death was often an unanticipated event for relatives:

Just before Christmas it was about three years ago he was really poorly and the doctor came out and said he had got 48 hours to live and of course two years later god bless him he passed away (K13 Nursing Home Manager)

You know I'd asked how long ...and he'd said how long a piece of stringis you know I mean fair enough , I mean.....But they kept sayingno she's not ready to die , she isn't ready (R4 Daughter)

Nursing staff echoed this sentiment describing the difficulties of knowing and informing relatives about the proximity of death;

The problem I think with death is its unpredictability and therefore I don't think there'll ever bea right place for people to die.... I think ... its lucky if you ... if you're able to die peacefully and quickly In your home surroundings (K10 Consultant)

This unpredictability and 'not knowing' was a common cause of feelings of regret for many relatives, especially if it meant that they were not present at the point of death:
I just didn't want to leave my mum... I had trouble with that because I always said to my mum...I'll be with you at the end; I should have been there (R14, Daughter)

You know I think she should have been made comfortable and we could have spent the last five hours with her – that's our regret... that we couldn't have the last hour, half an hour with her (R5, Daughter)

Care for relatives after someone has died

Relatives highlighted how vital, sensitive care is, in the period immediately after someone has died. Small gestures - as small as the offer of a cup of tea and some private space - had lasting effects whether they were relatives;

They brought us a tray of tea and they were fine. (R10 Wife)

But the hospital were very nice they just said stay with her as long as you like? (R6 daughter)

Or staff:

Well Its just where, whichever quiet empty room you can find There aren't any designated areas to do that It's just usually a little office where you can take the family members and tell thembut there's no special place really (K1 Chaplain)

Today I've been sat in a room.....with consultants and specialist nurses coming through that room.....not because they didn't want to but because they had no where

else to go and.....I was dealing with a family who were in terrific social melt down (K2 Chaplain)

Sometimes finding and handing over personal belongings seemed to be given a lower priority in the context of service demands;

They couldn't find my mums things, they couldn't find her rings ... It was only her wedding ring but they couldn't find it (R3 Daughter)

Another thing that upset me.... We took all my mum's bits away that they thought we'd need as you do.... and ended up with a sheep skin coat that was nothing to do with my mum (R14 Daughter)

Another problematic issue was the delay in obtaining signed papers concerning the death which have to be collected from the ward

We were told 'if you come at such and such a time, come up to the ward and we'll have it ready for you' ... We got there and the doctor hadn't done it and we had to wait about an hour and a halfand we kept going to say look you know we've got things to do, can you chase it up and they kept chasing the doctor and ...it did take ages and ages and you just want to get out of there don't you? (R1 Daughter)

Organisational issues

Whilst many of the issues were echoed between key informant and relatives there were some issues which were specific to key informants. Not surprisingly these tended to relate to issues of organisation and structure. For instance, care of someone with an intravenous infusion in hospital is normal practice however in a community environment due to lack of medical cover it is not. The concern about someone not drinking and getting dehydrated would often trigger the referral to hospital from either home or a residential or nursing home.

We can't run an IVI mainly because we haven't got medical cover (K12 Nursing Home Manager)

Each professional group involved in the patient pathway from community through to hospital was governed by a specific set of policies and procedures which served to affect the quality and continuity of patient care. The ambulance staff, for example, have

to attempt resuscitation, unless there is a signed, witnessed and correctly dated Do Not Resuscitate Order. This is unlikely to be held by people at home or in residential homes, but it is more likely if a patient is receiving hospice at home care. Residential home staff have to request or refer for medical help, since they do not have resident medical cover or senior nursing staff to deal with medical emergencies and reported not being prepared for dealing with end of life care.

Because of the lack of provision of out of hours care ... we get called out so many times to people who have ... died some time before... but there is a lack of provision, in the community setting for Active Do Not Resuscitate Instructions (DNR's), The family will then say... I don't want my mum , partner, mother, whoever resuscitated.... My crews have an obligation... unless there's an active DNR to show, witnessed to, signed and correctly dated We have to resuscitate ... and it's a horrible thing to put the families through (K7 Ambulance Service Manager)

Interviewer: *If you have any infections or anything that needs nursing care, I know you've got the nurses up there so you wouldn't need [to call in] any district nursing or stuff like that*

Respondent:

No you have to legally, it's a requirement ...for a residential floor ... they are clinically employed for that role (K11 Manager Residential and Nursing Home)

The hospital staff seemed to feel that there was a lack of a palliative care pathway within the district hospital. despite the professional belief that a clear selection of referral pathways existed, a palliative care professional felt that not all options available were being used by GPs or by the service users as envisaged:

I can't detect that there is a policy or system or a protocol that guides patients through the hospital in this respect and that's all I can think of (K1 Chaplain)

There isn't for example a palliative care pathway in this hospital, so that when a patient really is dying, you can't easily enter them onto a palliative care pathway which we used to have in another trust (K10 Consultant)

There's no cohesive policy or agreement about how you should deal with palliative care patients, you know patients facing life threatening illness (K1 Chaplain)

We would usually get between 20 and 25 referrals a month and we probably have about 18 deaths a month, so I would say our average monthly case load would be between 20 and 25 really, patients ... Not many at all refer themselves ... Never GPs...(K17 Hospice manager)

Also, out of hours services were frequently unaware, despite having an explicit information protocol, of any special palliative needs existing in the community. Perhaps, due to these issues around referral mechanisms, patients most commonly arrived at the hospital via the ambulance service. Whilst this pathway was substantiated by the relatives and many key informants, the ambulance service was not so sure.

GPs should be making us aware of any patients who have got special needs, i.e. palliative care, mental health, anything that would facilitate our ability, or help us deliver the care as necessary for that particular patient. Probably the most common one we get is palliative care (K16 Out of Hours Manager).

Interviewer: Would an ambulance... A Paramedic... always bring some one to hospital?

..In Coventry and Warwickshire we only convey 65% of our total calls...and our emergency care practitioners are only conveying 40% (K7Ambulance Service Manager)

Directly linked to these moments of referral, but also woven throughout the care pathway, was both an implicit and explicit need for staff training and development and a feeling that sometimes, staff in residential and nursing homes may not have the confidence to argue for a patient to stay in the home rather than being transferred.

. . I think the problem, is ... GP's that don't realise the depth of care that we actually give in a nursing home And sometimes its difficult to Staff that haven't got the confidenceto stand up to a GP or say, this resident doesn't want to go anywhereI think that's particularly relevant when we have junior members of staff, trained staff or perhaps foreign nurses who aren't as experienced as my existing staff (K14 Matron Nursing Home)

Some of the requirements highlighted were addressing the professional and carer's need to understand and support the process of dying. It was clear that carers at home need reassurance that not eating or drinking when close to death is normal and that not all health professionals offer this consistently.

I think; you'll go in one morning and then they'll say 'oh I couldn't get anything to drink or eat down him yesterday'. Once they've told you that, then you have got to go with it and sort of reassure them that things may be changing now okay, so if he doesn't fancy much to eat, don't worry, don't force him, you'll just put him off even more, the more you try and force. So I think its just as the problems arise, deal with it then, but then the issue we would have is somebody following us in and saying, ' Oh if he had not drunk for 24 hours, he needs to go into hospital because he is going to be dehydrated, and if he has not passed urine, he'll probably need a catheter, so that's where the damage happens I suppose in a lot of this work... (K17 Hospice Manager)

if I had my ideal ... I would want Some of the wards to have sufficient levels ... to look after sort of perhaps ordinary death (K9 Consultant)

At other times, training requirements were identified more specifically by staff.

Over the years we have asked for counselling... we did receive a small amount of counselling and training in how to react to peoples' grief but we've never really had that on an extensive scale ... Basically the idea would be to have training on the right things to say and to react in when we're confronted with aa grieving relative That would probably be the most sort of suitable area of training for us, we've never really been given the opportunity to have that (K4 Porter)

Training is considered important but in reality it is often difficult to attend owing to staffing constraints;

I've always said to the nursing staff obviously they have to go on their own competencies at the moment, but if you felt that you could go out and make that patient's life better, then do so, and you will be supported by the PCT (K16 Out of hours manager)

We do acknowledge that staff training has changed in the last few years and know that one of the reasons is because nurses find it difficult to get off the wards to do mandatory training as well as continuing professional development (K3)

The method of the delivery of training varied and was not always specified, although shadowing experienced practitioners was considered appropriate. This idea was raised in focus group meetings where health care workers were keen to learn more about each others roles. Unmet staff training needs were identified commonly within nursing homes and hospitals. Staff clearly felt that these needs impacted on their ability to provide for

patients physical well being and comfort which was considered to be of paramount importance at this point in the pathway of care.

I think that it would just be nice that if.....it were part of peoples training, part of peoples experience of whatever level on the ward that they.....spend some time...say shadowing a chaplain or.....just to get some experience and it should be compulsory (K1 Chaplain)

The importance of communication between patients, family members and health professionals was a critical area raised by both relatives and key informants. Failure to communicate well led to a variety of negative emotions which remained powerful over twelve months later.

Every time she's had something, bad news, every time she's always been on her bloody OWN. (R13 Husband)

She said I'll get the district nurse to phone you on Monday so we got him home... We heard nothing from the district nurse ... but he was definitely going down hill by Wednesday night...I still heard nothing from the district nurse and I was getting quite frightened actually (R20 Wife)

They took us into this room and I must have been there for a good half an hour... before they come and told us whether she was alive or dead My sister in law used to work at the hospital and she got quite angry..... You know she said it shouldn't take this long to come and tell you what it is. I was just sitting there totally knotted up not knowing... well I knew in my heart that she was gone (R7 Daughter)

However even in situations of despair and anger, the ability to communicate well could diffuse the situation instantly and soften the memory

This bloody fool of a doctor came out with all these high fluting long words which I'm not even going to try to say what they were but anyway the little nurse who like I say I can't speak highly enough of .. well she could see I was upset ...not tearful, I but angry upset She said 'Is there anything I can do?' and I said yes sweetheart just tell me what it all is and she spent five minutes I should think ... and she went through everything and she said' what's happened is this has done this and that has done that and the others done the other and to cut a long story short he's on course for having a massive heart attack and that is what he's going to die of' (R22 Carer)

Study Aim 3. To identify critical junctures of referral and care decision making and to work with key professions and personnel to improve end of life care.

Many of the decisions made at critical junctures along the pathway occurred as a result of complex interactions such that simple interventions were not always obvious. Interviews with relative and key informants helped identify and clarify the trigger incident or situation that led to the call for help that started the patient journey. These frequently related to lack of help, which was manifested mainly in the form of a pronounced and urgent need for support whilst caring for someone at home. This need was either physical (R11), emotional (R20) or a combination of both (R15) was the trigger for calling a doctor or the emergency services.

Well I couldn't rouse her, she was like asleep. I tried to wake her up sort of thing, any road I know if was here I would have gone straight to her because I'm not good with things like this. Any road she wasn't here so I went to our mate to come and help. It was on a Sunday and he said get the doctors but they'd be nobody there, so he said the emergency service. (R11 Husband)

You know, I think he was frightened and in the end I phoned I said 'Shall I phone the doctor?' and he said 'Yes... so I phoned the doctor and of course ... they go to the hospital don't they now (R20 Wife)

He'd got chronic diarrhoea Well what actually happened was he was dehydrated... I mean now looking back I can see what happened... but at the time it's very difficult because you're trying to work, you're trying to look after him... I was extremely tired, I was on my knees... (R15 daughter)

Nursing Homes

Within nursing homes, patients were often transferred to hospital for an intravenous infusion to treat dehydration. Staff at nursing homes were clear that intravenous therapy could not be supported in the nursing home due to number of nurses, nursing competence and home policy. Patients nearing the end of their lives tend to refuse to drink and so are at risk of dehydration. Knowing that patients are dying and that this is a normal part of the dying process is likely to affect decisions made at this point on the pathway.

Often medical professionals called to see patients at the nursing or residential homes, asked the nursing home staff what the relatives wanted the doctor to do – i.e. send to hospital or stay at the home. This was especially true if the dying patient was unknown to the doctor.

Even proactive nursing homes where the Gold Standard framework (GSF) for End of Life care (EOLC) had been completed, still struggled to deliver EOLC, finding that local doctors were reticent to provide stock controlled drugs in case their use resulted in the death of the patient. One comment from a manager of such a home stated that doctors seemed to have anxieties about the findings of the Shipman Inquiry.

In other cases, the doctor or nurses had no choice but to transfer the patient to hospital, as relatives insisted on this. In some cases it appeared that this was related to the family relationship with the nursing home – if family perceived that the nursing home was not providing good care, they were more likely to insist on a transfer to hospital. In other cases, relatives and professionals were simply unaware that death was so imminent, often remarking that if they had known then would not have moved the patient

Transfers from home.

There were several instances where relatives and carers felt that transferring their relative to hospital to receive end of life care was appropriate. Knowing that they were near the end of life would not have changed their decision. However for many relatives and carers the lack of awareness of how imminent death was, did affect their decision. As decisions to transfer to hospital were much more likely to be as a result of carer exhaustion, coupled with a lack of support, (this was especially true if transfers occurred during the night), knowing that the patient did not have much longer to live may well have prevented this move.

Other transfers to hospital were made, even when it was clear that the relatives were trying to let their loved ones die at home. Exhaustion, fear and sometimes panic seemed to trigger the need for immediate help. These cases were particularly poignant and served to emphasise the lack of support and help available within the community which resulted in the move to hospital and often left the relatives with a sense of failing their relative's last request.

As patient transfer was always by ambulance, if the transfer was via a 999 call, the ambulance crew assessed each individual situation to see if the patient should be

transferred to hospital. They commented that where advanced life directives were in place they were not always able to use them in the decision making process because they were often not up to date or created in accordance with the ambulance policies and protocols.

Transfer by the emergency ambulance service meant that patients were always admitted via the A&E department. As government targets are that no patient should spend longer than 4 hours in Accident and Emergency, patients were often moved to the emergency medical unit (EMU) where they stayed until a bed on a ward became available. In such cases this meant that patients and relatives experienced moves three times within their last 48 hours of life.

Whilst there were few criticisms of clinical care during this time and with these moves, relatives reflections focussed more on the quality of care – the disruption associated with moving from place to place, the impact this and the environment had on the personal and private time with their dying relative.

This study found that for some relatives, had they been aware of the dying trajectory and been provided with access to swift support, help and advice it is likely that they would have died at home. For others however their preference was to die in hospital irrespective of the imminence of death or level of support in place. There is therefore a challenge for district hospitals and nursing homes to offer end of life care that is person centred and which allows death with dignity, whilst meeting the needs of relatives within the spatial, clinical and administrative conditions by which staff are constrained.

Study Aim 4. To improve the patient care environment for end of life care.

To achieve this aim, six group interviews with staff in nursing and residential homes and in the hospital were completed. A participatory technique known as an H diagram was used to ask staff to identify how well they felt end of life care was currently being managed by their organisation. This was completed prior to the presentation of the study findings to each group. Once the study findings had been discussed by the group, they suggested possible interventions which would improve end of life care within their organisational setting.

The staff identified several areas where improvements could be made.

- Identification of a number of palliative care beds within the acute hospital setting

- Increasing the number of single rooms for patients nearing the end of their lives.
- Provision of targeted and specific education in building confidence among Health Care Assistants caring for patients at the end of life – utilising the skills, knowledge and experience of Hospice at Home team.
- The possibility of a flagging system which would allow patients to choose whether to come into hospital or stay at home
- Exploration of bypassing Accident and Emergency and being admitted to the Emergency Medical Unit.

Study Aim 5. To develop nursing research through capacity building and leadership.

A programme of activities aimed at building individual and institutional nursing research capacity was carried out as part of this study. All three nurses employed in the study were able to develop research skills. Only one of these (JP) had any previous formal research qualifications, the other two were seconded from clinical practice. These two nurses learnt how to interview, transcribe and carry out a literature review. In both cases they have returned back to clinical practice and are keen to pursue research in their daily activities. In addition, work was conducted at the district hospital and a short paper on this has been published in the Nursing Times (Purkis et al 2008) and is in the Appendix. A scoping exercise was carried out using a simple, short survey to map the level of research knowledge, activity and experience of nurses working within the Trust and capture any areas of practice which the nurses were interested or involved in. Approximately 400 were distributed by hand to qualified nurses. Whilst verbally nurses expressed interest in research and promised to complete the questionnaire only nineteen responses were received. In order to reach more staff to identify what were their preferences in terms of training format and content, two road show sessions were organised for staff on site. Subsequently fourteen further members of staff from various disciplines contributed and advised on the most preferable arrangements. This provided the research team with a framework and ideas of what staff wanted to learn.

Workshops were designed as informal drop in type sessions run across four consecutive weeks ideally on the same day each week. The rationale for this was to try and develop some continuity and familiarity amongst the staff. These were carried out late 2007.

During this time, many nurses seemed to recognise that researching could indeed be part of the work that they did and evolve from things they were already doing rather than requiring substantial amounts of extra time. However they felt they needed a clearer

understanding of how that could work in reality. Initiatives such as those described here can be instrumental in supporting and developing both characteristics of the individual and demystifying research which may also help with issues of accessibility.

Within the hospital trust, the team have been invited to have ongoing involvement in the management training of nurses at the point of qualification have presented at grand rounds, were invited to second hospital Trust Nursing conference in Sept 2008. In addition the team have had representatives on the Mortality Committee since its inception and have presented to the Dissemination of Audit, Research and Evaluation group.

Nationally, the study findings have been presented at the Royal College International Nursing Conference in Harrogate, in the seminar series of the University of Warwick, at the Strategic Health Authority, End of Life strategy meeting and at Local Trust Board meetings. Academic papers are in preparation and abstracts have been submitted to national and international conferences during 2009. Of particular note is a paper to the 16th International Learning Conference on work based learning within this project and two papers to the 2009 Delivering Better Health Services, Health Services Research Network and National Institute for Health Research SDO Programme joint annual conference.

Knowledge transfer and follow on work continuing in 2010

Applied theatre

An applied theatre performance on End of Life Care drawing on the issues from this study is being developed. A theatre director, Claudette Bryanston who has worked with Lewando Hundt on two previous studies (Stuttaford et al 2007), has been awarded a Creative Fellowship at the Centre for Excellence in Performance, Teaching and learning (CAPITAL). This Centre is a jointly run by the University of Warwick and the Royal Shakespeare Company. The Fellowship is to develop a performance through working with staff and students, drawing on the themes from the data in this study. The performance will be called 'Passing On'. Further funding for this is being sought to perform this with panel discussion in hospitals, nursing homes and residential homes during 2009-10 as a professional development activity to build capacity in end of life care. This is part of a portfolio of innovative work in Applied Theatre in Health and Social Care at the Institute of Health.

Further research

The hospital chaplain with support from the research team, has developed a funding proposal for developing and piloting a spiritual tool, has been requested He has applied for funding from the Strategic Health Authority.

The research team is proposing to apply for funding with the Hospital Trust to the National Institute for Health Research, Research for Patient Benefit, to pilot a palliative care pathway at the hospital. This takes forward suggestions by health professionals elicited during this study.

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Appendix

Publication Sept. 2008 'Increasing Nursing Research Capacity in the Workplace'
Nursing Times, Sept 16th, pp28 – 31.

Increasing Nursing Research Capacity within the work place: experiences in a hospital trust

Authors: Purkis,J., Jackson,J., Stockman,C. & Hundt,G.

The context

Engaging nurses in research both in terms of doing research or employing research findings remains notoriously difficult (Lacey 1994). Much research and therefore research funding has historically remained within the domains of either academic or medical institutions but there is increasing impetus for this to change (Hutchinson & Johnston 2004, DOH 2006). Best Research for Best Health (DOH 2006) clearly outlined the Governments vision for an efficient and effective Health service underpinned by top quality, leading edge research. However, it also advocates a clear and consistent focus on the needs of the patient and the public. Needless to say then that, amongst all health professionals, nurses and especially those in clinical practice, should be in a prime position to maintain that focus and drive that research agenda. This builds on the strategic objective of the former policy document 'Making a Difference', "to strengthen the capacity of the nursing profession to contribute to and to undertake health services research" (DOH 1999).

As with many other allied health professions, research teaching is now an integral part of the nursing curriculum and increasingly post qualification professional development requirements encourage a research orientation. Nevertheless, within a profession with an ageing demographic (NMC 2007) there will remain some practitioners for whom research may remain a distant and foreboding spectre. This, along with many other factors ranging from "particular attributes of individuals at one end of the scale to widespread organisational difficulties at the other" (Bryar et al 2003, p73) may mitigate against clinical nurses involvement in research. This paper sets out to describe how, on the site of one hospital trust, three nurse researchers set out to investigate and encourage practitioner engagement in research and describes the challenges of that journey over an eighteen month period.

Literature review

Much of the literature focuses on transfer of knowledge and/ utilisation of research findings in practice to develop evidence based practice. Much less is available with regard to developing research capacity in clinical settings amongst currently practising nurses. This is despite an awareness of the problem for many years (Llorens and Gillette 1985) and a critique of the paucity of the literature more recently (Sergott 2006). Engaging nurses in research and the creation of knowledge offers the opportunity for nurses to move beyond being purely “research consumers” (Winter 1990). By developing ownership of their own clinical concerns consequent research may begin to reduce the research-practice gap. It is therefore crucial that opportunities are available for practising nurses to engage in research should they wish to do so. However, creating a clinical research culture and increasing nursing research capacity is not necessarily straightforward.

Sergott et al (2006) identified a variety of important challenges to developing research capacity amongst nurse educators, albeit in academic departments. Their review of the literature suggests many challenges facing nurses and emphasises the need to understand the local context as well as possible. There are some recurring and key themes that may help guide future developments. The two main themes in this study were;

- Material constraints and organisational contexts
- The changing roles and expectations of nurse[s] ([or] educators)

(Sergott et al 2006)

We will see these echoed as we later describe our findings.

Funk et al (1991) looked more specifically at research utilisation but inevitably this required a consideration of the local nursing context. This work considered the challenges in trying to progress or develop a research culture in nursing. The model which Funk developed in fact took its base from the work of Roger's (1983) who, when exploring the diffusion of innovation, suggested that there are four main factors important to the adoption of change; the characteristics of the adopter, the organisation, the innovation and the communication. Funk (op cit) translates these for the purposes of application to a clinical setting to correspondingly; the characteristics of the nurse, the setting, the research and of the presentation and accessibility of research.

Adams (2001) conducted a small phenomenological study exploring the research perceptions of qualified orthopaedic nurses. Specifically the setting and the research were reported as most important to this group of nurses. Furthermore Bryar et al (2003) suggest that historically organisational constraints have been paramount which could add weight to the setting being key. Conversely however they indicate that for this studied cohort of nurses practising in the North of England, the main barriers to utilisation were not necessarily reported as 'organisational' ones. In fact what was reported were issues of time, lack of individual authority, issues with the research itself and lack of peer support. This is important and is reflected later in our discussion.

Setting up

Funding was secured for a nurse led research study in a district hospital. Included in the funding was a component for building nursing research capacity – a specific aim of the funding body, the Burdett Trust for Nursing. The original research design planned for two or three nurses to be seconded, with back fill to work part time on the study as practice based researchers. When advertised within the hospital there were very few interested candidates so eventually one registered nurse was seconded full time and a plan developed to raise awareness of opportunities for practice based research and stimulate interest in them. The principal investigator (JAJ) had previous experience of developing health improvement projects on wards with staff in another hospital trust that resulted in successful external funding.

On site assessment

Initially the researchers developed a simple, short survey to map the level of research knowledge, activity and experience of nurses working within the Trust. The survey also aimed to capture any areas of practice which the nurses were interested or involved in and approximately 400 were distributed by hand to qualified nurses. This one page document offered nurses a choice of research topics they may be interested in e.g. literature reviewing, simple statistics and qualitative interviewing. Nurses were asked to tick those of interest to them. We also collected data on their previous experiences in clinical practice, audit and research. Whilst verbally nurses expressed interest in research and promised to complete the questionnaire only nineteen responses were received. This perhaps reflects the ongoing challenge of engaging practitioners described by Newman et al (1998). Despite this low response there was, among this

group of nurses, considerable interest in many areas of research, as shown below in Table 1.

Table 1: Nurse responses to survey; Topics of interest

Literature searching	12
Writing for publication/journals	13
Action Research	13
Simple statistical analysis	11
Poster/abstract preparation	8
Qualitative interviewing	9
Other (please explain)	3

Over half of the nurses had previously been involved in audits or benchmarking activities. Their areas of interest generally related to their current areas of practice and spanned numerous specialist areas.

In order to reach more staff to identify what were their preferences in terms of training format and content two roadshow sessions were organised for staff on site. Initially the venue of the “stall” was within a purpose built training centre, situated next to the main hospital site. This proved to be poor choice as no staff were ever incidentally passing by and its location was removed from the clinical practice area. We relocated to a more central and visible position - outside the staff canteen – thus ensuring that we had a steady stream of all grades of staff, both nursing and AHP passing by. Fourteen members of staff from various disciplines contributed and advised on the most preferable arrangements. Most importantly the decision was made that any future activities should be held in the main hospital, in areas near the staff canteen which has a high level of staff activity throughout the day. This made the team much more visible.

In terms of location, timing and advertising there was no consistency of opinion from the 14 respondents. This perhaps reflected the diversity of different practice areas with different clinical demands. There was more consistency regarding the time than anything else with most suggesting that afternoons were more suitable.

Perceived Challenges

As table 1 demonstrates, of the initial nineteen responses to the questionnaire twelve nurse had identified that they would like help with reviewing literature, thirteen had asked for more information and support with writing for publication and a similar thirteen had hoped for increased understanding of research methodologies. Verbal responses from the other fourteen members of staff had included things such as “would like to be involved if I knew a bit more” and “I am very interested to learn and update skills”. This provided the research team with a framework within which to plan the next stage.

Workshops

Workshops were designed as informal drop in type sessions run across four consecutive weeks ideally on the same day each week. The rationale for this was to try and develop some continuity and familiarity amongst the staff. Due to the lack of availability of the room we were unable to book the same day each week, although eventually this became of no importance, the reasons for which will become apparent.

Prior to the workshops, a brightly coloured, eye catching poster was designed and displayed all around the hospital. Also, an advert was placed in the hospital bulletin which was available to all staff on the hospital intranet Furthermore, personal email invitations were sent to all heads of department, ward managers/team leaders and specialist nurses. We felt that the workshops were well publicised and we anticipated a lot of interest.

In response to the concerns that had been identified the chosen topics for the four consecutive workshops were; ‘What is research?’, ‘Literature searching’, ‘Methodologies’ and ‘Writing a paper’. We developed a short power point presentation for each topic and each week’s topic was added to the one before. We planned to then use this as a rolling slide show throughout the workshops. Additionally there were display boards containing information, examples of research posters, contact numbers for the team and also details of the hospitals own research and development department. Handouts were developed and as an added incentive to encourage staff to approach the table, a large tin of chocolates was available.

Implementation

The first workshop was organised and set to run on a Tuesday in mid November 2007 from 12.00pm until 2.00pm, hoping to catch staff across their lunch break. We set up the initial part of the power point entitled ‘What is Research?’ to roll on the wall of the

conference room. This room was adjoining the main canteen, with two sets of double doors. We arranged the display boards, set out handouts and sweets on a large table and waited for some interest.

Using this room however proved problematic, the room was perceived as a very separate area and we were effectively shut off from the public area, the canteen, with the doors creating a physical barrier (although they were open). It had the feeling of an empty shop – no one wanting to be the first customer. So, despite all the publicity and invitations we had virtually no interest and had to rethink our strategy.

The following week we decided to abandon the conference room and with the canteen manager's permission moved directly into a corner of the canteen. We set up the display boards as before and added the next small power point presentation, 'literature searching' to the rolling display. This was projected onto the canteen wall for all to see.

The difference was immediately apparent as people appeared curious and seemed to be taking an interest in the display and slide show. However, we continued to sit waiting for more specific enquiry. We knew that there were nurses in the hospital with an interest in research and some feasible ideas circulating in practice, but still virtually no-one approached us for help or advice. As our finish time of 2.00pm approached two student physiotherapists came up very apologetically and asked for some help as they were about to start their dissertations. They were unsure about how to commence their literature review. Whilst we seized the opportunity to help we were fascinated and informed by their observation that they had thought we were in fact there "waiting for somebody important". We obviously, in their eyes at least, had not seemed approachable.

Workshop three went ahead as planned. Despite the poor level of interest to date, we hoped that by providing a consistent and eventually 'familiar' presence, interest would gain momentum and indeed this seemed to be the case. Whilst we did not have an abundance of interest in week three, one or two people approached us and asked simple questions and took away some of the prepared handouts. There seemed to be a definite, if slight, improvement. However, we were then approached by a lunching consultant with an obvious interest in the slide show. She was very polite and keen but slightly concerned about the nature of some of the content in the slide show. Specifically, as our own topic was fundamentally about end of life care and we had used some of this as examples for research, i.e. as keywords, words such as 'death' and 'dying' she felt this may distress some people in a public area. Whilst this is a debatable

notion, particularly in a hospital environment, it was also a valid observation and easily resolved. In order to avoid any potential for distress or discomfort we agreed to remove these examples and insert others. This was done in preparation for the fourth and final workshop.

The last workshop was again held in the canteen. The slide show had additional information added on the subject of 'how to write a paper' and our displays and handouts were readily available as in previous weeks. The uptake was slow but sure and three or four valuable contacts were made.

Discussion

During this short time of contact within the trust we had undoubtedly established a trickle of interest. Whilst 'time', a characteristic of the setting, was repeatedly given as a reason for avoiding participation in research this was actually less of a concern than lack of understanding on the part of individual nurses. The only other concern equal to lack of understanding was accessibility of the research itself. Whilst the setting remains crucial, fortunately, these latter key concerns may, in the short term, be more immediately and realistically addressed. Many nurses seemed to recognise that researching could indeed be part of the work that they did and evolve from things they were already doing rather than requiring substantial amounts of extra time however they felt they needed a clearer understanding of how that could work in reality. Initiatives such as those described here can be instrumental in supporting and developing both characteristics of the individual and demystifying research which may also help with issues of accessibility. Whilst, in part, the answer may ideally be to add some protected research time built into nursing contracts in the current context this may not be attainable.

Subsequently we emailed all the clinical nurse specialists, ward sisters and charge nurses within the Trust reiterating the importance of research both as knowledge to inform practice and as a process and lever for change. We reminded them of both our availability and the support already in house. We have already been contacted by two clinical nurse specialist requesting advice on ideas for research. Following liaison with the professional development nurses on site a research element is being designed for inclusion into both the management training provided on site just prior to qualification and in regular mandatory training. In doing this we hope to be able to maintain an interest and dialogue with front line staff with regard to practitioner based research hoping that ultimately nursing research on site becomes integral to best clinical practice.

Conclusion

This initiative has highlighted once again the tensions between service demand, nursing capacity and nurses research confidence and capabilities. An important learning point for this research team is to remain flexible, proactive, creative and enthusiastic in supporting nurses to develop their skills. It is useful to summarise the lessons learnt for others considering any similar pursuit.

- We found that generating interest clinically is challenging and one should anticipate a slow build up.
- Consistency and familiarity seem important in provision.
- Support and information is more likely to be accessed if taken into the vicinity of practice.
- To be well received, ideas need to be generated from clinicians themselves.
- Accessibility of information with take home materials are popular.
- Flexibility and adaptability are key.

The process described here has resonance with much of the literature in that reconciling the clinical demands of practice and the pressing urgency to foster research cultures remains one of the major challenges of the modern NHS (DOH 2006).

Implications for practice and future plans

This project seems to present a microcosm of research dilemmas in practice. The nursing staff harboured the most imaginative, impressive and important ideas for research, they had even begun, at times, to suggest potentially simple, sometimes creative solutions to the dilemmas they saw. However, few recognised their daily challenges and observations as research material; less still had any idea how to go about developing these ideas into a proposal worthy of funding. This uncovered a lack of good, structured, practical support taken to the clinician in their own space. Whilst support was available in the teaching centre and the library, by the very nature of its location away from the clinical area it allowed research per. se. to disappear from the everyday agenda of practice. Nevertheless, partly as a result of our brief period of clinical visibility, we have been invited to continue our input within the management training and mandatory updating. This is intended to regularly reminding nurses that a critical, analytical view of their everyday practice is the germination of research and the

foundation of evidence based practice (Fitzpatrick 2007). Furthermore it is designed to ensure that the infrastructure of support is there to help individuals when they are ready to develop their own ideas and practice.

Undoubtedly the profession now stands at a crucial point in the history of nursing research. The policy is firmly in place and the public rightly anticipate health care based on the best possible research. The onus now lies not only with individual clinical professionals and clinical leaders but with managers and researchers alike to collaborate on finding the best possible ways of fostering and nurturing dynamic and healthy research cultures.

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