PRACTICE DEVELOPMENT PROGRAMME EVALUATION
PRIVACY AND DIGNITY IN CARE

BACKGROUND

The purpose of this paper is to present an evaluation of a programme of practice development that brought eight nurses and eight older people together to explore the meaning and challenge the popular understanding of dignity in care using the creative arts. For the purpose of the programme, practice development is defined as being:

‘…a continuous process of improvement towards increased effectiveness in patient centred care. This is brought about by enabling health care teams to develop their knowledge and skills and to transform the culture and context of care. It is enabled and supported by facilitators committed to systematic, rigorous continuous processes of emancipatory change that reflect the perspectives of service users and service providers’

Garbett and McCormack, 2002

The eight older people, recruited by Age Concern Islington, had all had a hospital experience within the past year, the eight nurse participants came from acute inpatient services. This pilot programme (in part) can be seen as being a key piece of follow-up work relating to a focus group hosted by Age Concern Islington that explored older people’s experience of dignity in care within the Trust (UCLH 2007).

The programme that formally ran for six months was hosted and supported by Age Concern Islington and facilitated by an Independent Consultant in Creative Arts, a movement artist (for one of the sessions) and by the Consultant Nurse, Older People within the Trust.
ENABLING DIGNITY IN CARE BY USING THE CREATIVE ARTS

Dignity in Care

Achieving dignity in care with older people that is embedded and sustained in how both individuals and teams practice remains challenging (Webster 2007) and problematic although much national attention has brought this agenda to the fore (DOH 2008, DOH 2006, Age Concern 2007, Healthcare Commission 2007, RCN 2008). Defining what is meant by dignity is complex as there is little empirical research to show how older people view dignity (Woolhead et al 2004). It is argued that the concept of dignity is highly abstract (Chinn and Kramer 1999) and cannot be measured directly (Fenton and Mitchell 2002) or easily through traditional methods of measuring performance and outcome. Although dignity within the context of older people is frequently discussed in healthcare literature, its meaning is not always clear (Jacelon et al 2004) or well defined.

Recent national campaigns have highlighted how promoting and enabling dignity in care remains difficult to sustain in some areas. In their European Union funded study, Calnan et al (2003) identified that dignity was important to older people, although they found it easier to talk about dignity negatively focusing on its absence or when they had been treated in an undignified manner rather than clearly defining dignity as meaning something specific. Similarly when speaking with nurses about dignity, what becomes clear is that the term means different things to different people based on individual values, beliefs and experiences. This provides the key challenge when helping practitioners to explore and subsequently reflect upon and question their practice as it is essential to firstly find a common definition for dignity and secondly understand the impact of undignified care on the older person.

Using the Creative Arts in Clinical Practice

The use of creative approaches to help practitioners explore their practice has been discussed by different authors (Coulson and Stickley 2002, Williams 2002, Coats et al 2006, Coats 2006a). It has been suggested that art activities encourage individuals to ‘externalize’ and to give meaning to inner thoughts and feelings, to express ‘out there’ what is normally ‘hidden’ or not expressed (Coulson and Stickley 2002).
The use of art work can also be viewed as a means to assist personal expression in communicating feelings that normally may be hard to articulate or verbally describe (Williams 2000) in which creativity can enable greater emotional intelligence (Coats et al 2006). Freshwater (2004) identifies that through creativity, greater emotional intelligence can occur which provides an opportunity to learn both about oneself and the way in which we relate to patients and colleagues in the work place. As such this can enhance both our own professional effectiveness in patient care and how we nurture creative work place cultures (Coats et al 2006).

In helping individuals to explore their practice with older people, the creative learning approaches used in this programme of practice development together with the reflective learning helped participants openly to explore their thoughts, feelings and experience in an environment that was supportive, nurturing and enabling. Every session was a mix of in-depth discussion and creative work. Participants chose whether they wished to express themselves creatively, verbally or both.

As part of this programme of practice development creative work was used for a variety of purposes which included: creating shared understanding of what dignity of care meant to each participant, helping to express difficult experiences, and as a way of reflecting on and making sense of the experiences discussed during the sessions. Where this programme of development was different from traditional methods of learning is that it aimed to enable health practitioners and older people to learn from each other through immersion in the lived experience of patients’ care experiences, and their needs and expectations as older people receiving care. Such experiential learning took participants on a journey in which they were actively encouraged to question, share and reflect through skilled facilitation and work based support.

PROGRAMME STRUCTURE

The creative arts sessions ran on five occasions and were made-up of a variety of approaches to help participants explore their understanding of dignity in care; these included the use of collage, movement/dance and sculpting with clay. During the sessions participants worked individually, in pairs, small groups and as a whole
group sharing their stories and experiences about the meaning of dignity, and attitudes and factors that contribute to sustaining dignity of care or contribute to loss of dignity and privacy.

The purpose of each session was mutual learning aimed at supporting older people and nurses to work together to increase knowledge and understanding of the lived experience of hospital care in order to develop practice and enable improvements in care.

In addition to these sessions ‘reflective learning group meetings’ were held separately for the nurse participants (informal support was offered to those older people who took part if needed on an individual basis). Nurse participants were given reflective exercises/questions to take to their clinical settings to help them translate their learning from the creative arts sessions back into their clinical setting. The outcome of these reflective learning exercises was then shared by the nurses within the group as part of group reflective learning.

RECRUITMENT

Recruitment to the project was managed by the Consultant Nurse, Older People at UCLH (via discussions with senior staff and email invitations to the nurse participants); and by Age Concern Islington (ACI). Age Concern carried out a mailing and telephone exercise to recruit older people to the project, using a briefing jointly developed by UCLH and ACI.

Outlines for each of the 5 sessions were sent to all participants a week in advance of session dates. ACI carried out a telephone follow up with each older person participant just prior to the sessions to check on ability to attend, and arranged taxis to and from sessions for those who needed them.

Due to health needs, it was not always possible for older people to attend all five sessions. Four older people were able to make a commitment throughout the project, while others attended the sessions they could. All eight nurses were not always able to attend every session. This required flexibility on the part of the group.
and the facilitator to manage the uncertainty of not knowing exactly who could attend each session and openness to working with potentially different group sizes across the duration of a project.

OUTLINE OF SESSIONS

Session One
The aim of the first session was to support participants to begin to get to know each other, and to start to create a sense of trust and safety, so that they could share and engage openly with each other about their experiences of dignity. Participants introduced themselves and the older people gave some background on their previous hospital experiences. Ground rules were agreed within the group, and an overview of the programme was given. Participants then worked individually in making a simple collage focused on what dignity meant to them, and these were then shared in groups of four. From this there began to grow a shared understanding of the meaning of dignity for each participant.

At the end of the session evaluation of what had been useful included:

‘identifying what needs to be done to promote dignity and privacy’.

Another participant stated:

‘the creative work and group work’ and the fact that ‘the discussion groups were enlightening’.

These comments were then taken forward to the facilitation session held with the Consultant Nurse Older People, and clarification of the purpose of the programme was discussed further at the start of the second session. Before leaving the first session, the nurses identified learning to take forward into practice. This included:

- listening to needs more carefully
- checking assumptions and understanding what people want, rather than assuming
- giving options to patients and establishing relationships
Session Two
In the second session, the group explored in more depth specific behaviours and attitudes around dignity, i.e. the essential elements that sustain dignity and privacy of care, or contribute to loss of dignity. Following a short review of the previous session and the inclusion of new participants into the group, people worked individually or in small groups on sharing and expressing two experiences: one where their dignity had been sustained and one where it had been lost. The nurses did this by reflecting on experiences they had witnessed. This activity was done through a mix of discussion, writing, and use of college and clay to express and convey the essence of participants' experiences and personal meanings. Participants then shared their work in small groups.

There was a mix of responses to the process. Some participants found the creative work useful, while others found it difficult, though encouragement was given to choose whether to write about experience, use visual images or clay. The group discussed these issues together and practitioners agreed to report back at the next session on areas of improvement they had identified in their clinical areas to take forward. These were explored in more depth at the session with the Consultant Nurse Older People held in between each of the joint sessions.

Session Three
For the third meeting nurse participants identified areas for improving dignity in care within their clinical setting. During the session the group discussed together how to spread the message about dignity of care in each practitioner’s clinical area. Joint collages were created to take back to clinical areas, so that practitioners could share with colleagues older people’s views on the meaning and experience of dignity of care. This was developed by practitioners also discussing with patients on their wards what dignity meant to them.

Session Four
The fourth session involved using dance and movement. The group was led through a series of simple movement activities by a leading practitioner of Indian creative dance culminating in a poetic dance presentation.
One participant commented:

‘I found colours and movement so simple and enjoyed it very much. I learnt about needing to go at the pace of the patient, and guiding them through what they don’t know. To see the actual person’.

Another participant stated:

‘I got more than I thought I would by speaking up and having the opportunity to’.

The experience also stimulated reflections on: ‘how to reach people who can’t participate and are isolated in their own rooms’ and the provision of stimulating activity and contact in ward areas.

Session Five

For the final session the group invited guests from different organisations and from the participating funders to share their experiences and programme outcomes. The group made collages which summarised their experience of the programme, evaluated the programme overall, and discussed future connections and feedback on progress after the programmes formal end.

EVALUATION

Throughout the six months participants were asked to evaluate the programme as it progressed. Participant consent was sought at the final session to share their feedback in the report. Consistent themes that emerged focused on the usefulness of collaborative learning through sharing experiences, having open and honest discussions, and the sense of empowerment, one participant stated:

‘…it’s a partnership, been given a voice, listened to, and people are prepared to learn’.
Difficulties worked through included: hearing older people’s bad experiences, accepting failures of practice and how to address them, and from older people’s point of view, sharing painful experiences.

The nurse participants were also asked to share their learning with their teams and to identify work based projects that would help them both to embed their learning and support the development of others within their teams (see Box 1).

**Box 1. Work Based Projects**

1. Promoting increasingly effective communication between nurses and older people – use of patient diaries.
2. Working with the multidisciplinary team to ensure that dignity in care is an integral part of team meetings.
3. Introducing new initiatives and ways of working including:
   - Please keep quiet notices
   - A review of dividers to curtains
   - Performing theatre check lists in patient’s rooms
   - Ensuring patients are greeted on arrival in the department
   - Pre-operative visits to assess and meet patients
4. Introducing a ward based notice board focussed upon raising awareness of dignity.
5. Raising awareness of ensuring curtains are kept closed and that closed doors are not opened without seeking permission first.
6. Increasing vigilance at meal times to ensure all patients (who need help) receive support to eat and drink.
7. Increasing awareness of the need to encourage patients to wear their own clothing.
8. Looking at the environment of care – introducing music (as part of the Hospital Arts Programme).
9. Meeting as a dignity in care group eight weekly to review progress and agree new actions.
During the final session, held in March 2008, participants were asked to produce a collage (the subsequent discussion and feedback then informed the evaluation) to describe their learning and also asked a number of questions to evaluate the programme:

- What have been the main benefits and challenges of sharing and learning with practitioners and older people about dignity in care?
- How helpful or unhelpful did you find the creative methods and the facilitation for sharing your experiences and learning about dignity in care?
- If this project was repeated, what do you recommend new people are told about it?
- Are there other improvements you would recommend if this project was run again?

In describing their broad learning through the programme, one participant stated:

‘We’ve travelled on a long fruitful road. We have been through all possibilities that can be done in order for patients to be allowed their dignity; hopefully older people will overcome their fears of being hospitalised as a result of this.’

Another participant stated:

‘The discussions allowed me to open up and share experiences which have not been expressed before. I was comfortable but glad to get rid of the pain. The relief was immense’.

Participants described the broad benefits of the programme of practice development and the ability to share, communicate and learn together and subsequently influence practice through a greater awareness and understanding of dignity in care.

Raising awareness of the need to link the needs of the person to the dignity agenda was also highlighted:

‘...disability awareness should be part of dignity in care for everyone working in hospital care.’
The nurse participants also identified the challenges in engaging with colleagues and helping them to reflect and consider the importance of dignity in care along with listening to stories that were ‘painful’ to hear. The former was of particular relevance within teams that had a very technically centred culture. The group also recommended that introducing creative ways of working and collaborative learning needed more clarification at the beginning, as most of the group’s experience previously of understanding the service user’s perspective had been gained from focus groups, questionnaires or patient observation.

In identifying the helpfulness of using creative approaches to learning, participants described the value of creativity in releasing inner thoughts, feelings and emotions that would be difficult to share or express in more traditional ways. However it was also identified that using creative approaches to learning was new to the majority of participants and as such it took time for some participants to feel comfortable in using the creative arts.

Participants identified the importance of listening to each other actively, one person stated:

‘There was space to make my views heard and respected.’

Another identified that the programme would be:

‘…a catalyst for action.’

In describing their experiences of learning as a result of the programme the nurse participants now felt increasingly energised to take forward work related to dignity in care within their teams and recognised the need to work with the day-to-day challenges that they faced in their role no matter how immense those challenges may be.
SUMMARY OF KEY EMERGING THEMES

Participants described how the programme had clearly increased their knowledge, insight and understanding of dignity in care through:

- Exploring a complex concept in an imaginative and creative way.
- Learning from and ‘hearing’ individual stories related to older peoples’ lived experiences of dignity or loss of dignity.
- The benefits of joint learning and understanding.
- The potential of enabling effective communication through creative expression.

DISCUSSION

This programme of practice development took participants on a new journey to experience non-traditional methods of learning. For some participants, the ability to share a story about their experience of dignity enabled them to let go of previously hidden experiences and to move forward. Some participants found the ‘journey’ challenging as they were also adjusting to ways of working that required greater understanding and insight of essential, yet complex care. For some of the nurse participants the complexity of transferring learning back into work based cultures that were technically focussed also proved to be challenging.

Whilst release to attend the creative arts sessions for the nurses was achieved, the reflective learning groups were less well attended. The reasons for reduced attendance included: clinical pressures, shift patterns and ‘other’ commitments. This proved to be a limitation of the programme as the focus of the reflective learning groups was to help the translation of learning from the creative arts sessions back into clinical, work based cultures. Similarly for some older people attending all of the creative arts sessions was difficult due to health needs.

As a programme of practice development there were clear, tangible outcomes that included not only work based projects (see Box 1) but also a level of insight and
understanding based on joint learning and understanding that would have been difficult to achieved through traditional, technical methods of learning.

Transferability
The transferability of this work and style of learning and development to different settings is clearly evident. It is an approach which enables change to occur through joint learning, skilled facilitation and creative expression. However its success will be dependent on a clear commitment by all those involved (including commissioners, service providers and participants) to enable real, sustainable change to occur as without a tangible commitment and work-based support, outcomes will be limited. In addition, work-based cultures need to be open, flexible, innovative and nurturing as without this, experiential learning (that moves away from traditional approaches) will potentially wither and die and clearly not be sustained.

Learning from this programme of practice development
The need for buy-in and support from internal stakeholders at all levels at the outset should be made explicit with clear internal mechanisms to enable participants to share and develop practice within their teams both during and once the formal programme has ended. Work-based cultural preparation (understanding and working with) should form an integral part of the programme to enable nurse participants to understand, influence and work with clinical cultures more effectively along with ongoing support through guided reflection for nurse participants. In addition feedback needs to be established with those older people who have been participants to ensure that they are kept involved (if they wish) once the programme has been completed.

CONCLUSION
The ‘expert’ on dignity of care is the patient. There is a wealth of knowledge and experience that can be learnt from working with and listening to older people’s experiences – both good and bad. Programmes of practice development that aim to improve the older person’s experience of care need to ensure that the ‘lived’ experiences of older people are kept central and continuously heard. The programme highlighted that dignity and privacy in care is a partnership between an
older person and health practitioner, requiring mutual learning and sensitivity, which has to be learned through each interaction, open, skilled communication being central. Therefore dignified care cannot be assumed or taken for granted.

The engagement and support of the voluntary sector such as Age Concern was crucial in enabling effective partnership work between providers and service users. Technical cultures of care can act against providing dignified care - practitioners need the demonstrable support of their managers and colleagues in helping to transform patient experience of dignity and privacy in care. Collaborative, creative work enables in-depth shared understanding of experience, which can transform practitioner’s understanding of patients’ needs and create knowledge to develop and improve practice cultures and fundamentally the person’s experience of care.

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REFERENCES

Age Concern, 2006, Hungry to be Heard. The Scandal of Malnourished Older People in Hospital. Age Concern England.

Coats E, 2006a, Creative Arts and Humanities in Healthcare, Swallows to Other Continents – A Strategic Paper, The Nuffield Trust


Healthcare Commission, Caring for Dignity. A National Report on Dignity in Care for Older People while in Hospital, Healthcare Commission UK.


University College London Hospitals NHS Foundation Trust, 2007, Dignity in Care. Older People’s Experience of Care.

Webster J, 2007, ‘We all need to challenge practices that do not value a person’s right to dignity, Nursing Times, Vol 103, No 15, p 10.

Williams B, 2002, Using collage art work as a common medium for communication in interprofessional workshops, Journal of Interprofessional Care, Vol 16, No 1, pp 53-58