

ENHANCING SPIRITUAL CARE

CONFERENCE REPORT

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SUMMARY REPORT OF THE STUDY ON

Spiritual Care Education in Hospital Based Complex Clinical Care Units in one health board area in Scotland: A qualitative appreciative enquiry into spiritual care delivery by health care workers

Collaborative study between Faith in Older People and NHS Spiritual Care Unit
Ruth Aird and Maureen O'Neill

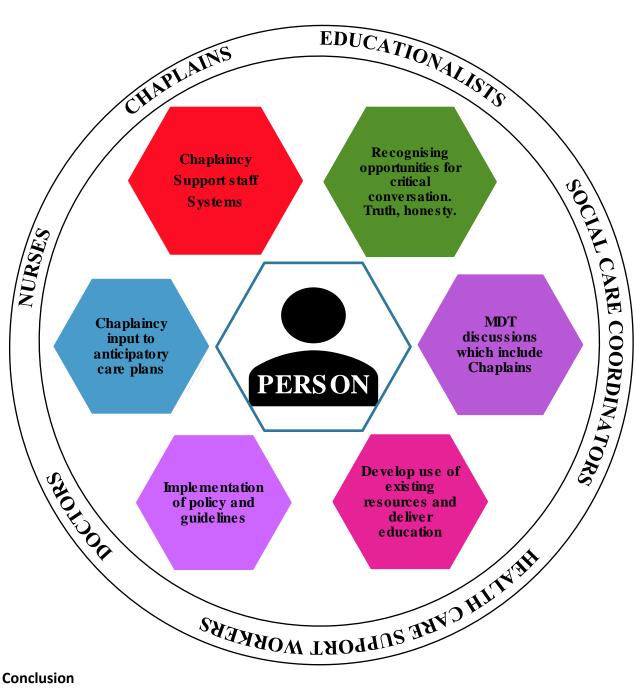
CONFERENCE REPORT

The conference was held on 17th May 2017 to consider the importance and awareness of spiritual care issues in a healthcare setting, the different practices in health board areas and the availability of education.

The focus of the conference was around the results of a study undertaken by Faith in Older People in partnership with NHS Lothian Spiritual Care Department.

The 35 participants were drawn from spiritual care teams, academics, HBCCC staff and Scottish Government which encompassed different health board areas.

SPIRITUAL CARE It's Everybody's Business Recommendations



Conclusion

The discussion corroborated the findings of the research project and provided opportunities to stress the importance of spiritual care. There needs to be further development of an evidence base to stimulate a more rigorous and consistent training programme in keeping with the integration of health and social care to better support the well-being of patients and staff. This must be inclusive of Care Homes, HBCCC's, Community connections, Social Care, Hospitals and General Practice.

SUMMARY OF PRESENTATIONS

Professor Robin Taylor, Consultant Physician, NHS Lanarkshire and Honorary Fellow, University of Edinburgh

More than organs – why spiritual care matters in hospital

Professor Taylor gave a robust, challenging and stimulating introduction to the importance of spiritual care being an integral part of care provided in hospital. It is important for the whole team to engage at the level of need of the individual patient and we need to be wary when following a mechanistic, guideline driven programme which might not have a benefit to the patient. Realistic medicine should include spiritual care and it is important that there is an emphasis on truth.

"Truth will set you free but first will p... you off".

He stressed the need to get over the taboos and enable patients to fully understand what is happening to them. Is there a tension between truth and hope and should doctors be custodians of hope? We need to have honest conversations and telling the truth must be an ethical responsibility to enable and support decision making.

There needs to be greater awareness of non- beneficial treatments as patients reach the end of life stage. This experience should not be "futile, burdensome and contrary to the patient's wishes" with little or no meaningful benefit; without harm or illusions of potential recovery and without a wasteful use of resources.

Hope and Grace

Spiritual experiences in severe distress, illness and dying

"Patients need spiritual caregivers who bear and permit intensive suffering while remaining silent and in whose presence, they dare to feel their anger at God and their fate.

Because solutions cannot be found without considering the question of God / fate, patients often need someone who ASKS them about God / the divine, their emotions, their feelings of forlornness and betrayal, and who does not shirk these issues".

Monica Renz. Kingsley Publishers. Philadelphia. 2016. ISBN 978 1 78592 030 1

Professor Robin Taylor's presentation can be found at www.fiop.org.uk

Carrie Applegath, Interim Head of Spiritual Care, NHS Lothian

Carrie provided the background to the research project which had been stimulated by Sandy Young when he had been the Head of Spiritual Care for NHS Lothian. He had been approached by a staff member in one of the Hospital Based Complex Clinical Care Units about the potential for more input from the chaplains. This was a challenge given that NHS Lothian was under-resourced in relation to spiritual care.

It was however important to be attentive to the need expressed and the project was devised which eventually had a focus on the spiritual care education for staff to increase their awareness and understanding of the spiritual care dimension,

She posed the following questions:

- How do we respond to the spiritual care needs of patients in hospital?
- What do we need to improve?
- How can managers support staff to articulate spiritual care needs and be confident about this dimension in care?
- How can spiritual care be embedded and integrated into care?

Rev Sheila Mitchell, Programme Director for Health and Social Care Chaplaincy and Spiritual Care at NHS Education for Scotland

The Rev Sheila Mitchell emphasised that **identity** is the essence of spiritual care. It engenders meaning and purpose and a sense of belonging. These elements sustain us and spiritual care is everyone's business.

Spiritual Care definition:

That care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self- worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. *Spirituality in nursing care: A pocket guide*. Royal College of Nursing.

She emphasised the following questions of the moment in relation to the policy context of the integration of health and social care:

- What are we asking?
- What's being asked of us?
- What are the challenges?
- What are the problems?
- What are the opportunities?

These questions must be seen in relation to staffing levels and capacity, the potential for burnout leading to compassion fatigue. This highlights the importance of collaboration and an understanding of how spiritual care support contributes to patient; staff well-being and resilience and how it can and should be everyone's business.

She highlighted the reduction in the number of chaplains in NHS Lothians and how the role of chaplain had changed and how the future is shaped by the current and emergent political drivers. Spiritual Care finds itself in the midst of this complexity so the challenge is where to go in the next five years. Spiritual care is in a time of transition and change which must adapt to an ever- changing NHS and to health and social care integration.

A response from the Chaplaincy Service was the work on Values Based Reflective Practice and Patient Reported Outcome Measures as reported by Chaplains and the Community Chaplaincy Listening Service.

She concluded that "It's not hard to make decisions when you know what your values are."

The presentation can be found www.fiop.org.uk

Ruth Aird, Interim NES National Co-ordinator for General Practice Nursing in Scotland and Faith in Older People Research Lead

Maureen O'Neill, Director, Faith in Older People

Ruth Aird and Maureen O'Neill presented the findings of the research study which was carried out in the nine Hospital Based Complex Clinical Care Units in NHS Lothian.

The methodology was that of appreciative enquiry with open ended questions. A total of 29 members of the nursing staff were interviewed. A literature search was also undertaken.

In undertaking the interviews, we were welcomed by staff for whom this was a rare opportunity to talk about spiritual care and their feelings about caring for patients who were in the end stages of their lives.

The aim of this collaborative project with NHS Lothian Spiritual Care Units was 'to examine the perception of spiritual care and its delivery in the HBCCCs, the resources available and the learning needs of staff.'

The criterial for admission to an HBCCC is based on one eligibility question:

Can your care needs be properly met in any setting other than a hospital?

Four themes emerged from the study:

- Individual narrative
- Person-centred care
- Educational needs
- Community involvement

Time was an issue that ran through the study.

The participants in the study echoed the emphasis that spiritual care is everyone's business. This emphasis was set out in NHS Education approach in Spiritual Care Matters 2007.

"Spiritual care in the NHS must be both inclusive and accepting of human difference. As we learn to listen better to the needs of different people, so we equip ourselves for work which is more effective and fulfilling. **The provision of spiritual care by NHS staff is not yet another demand on their hard- pressed time**. It is the very essence of their work and enables and promotes healing in the fullest sense to all parties, both giver and receiver".

The findings

- **Time** constraints were dominant "we never get staff breaks as there are only two of us and not enough time. We offer no spiritual or religious care too busy tasking. We are too busy responding so there is no proactive thinking. We do not even have enough time to get to know our patients.
- The relationship between **person-centred care** and time was very clear "I think the thing which would benefit the patient most is staff time it is easy to refer and tick a box but we need protected time to sit with a patient and just be with them."
- Understanding spiritual care was mostly understood as 'religion' and in this context staff felt that they needed support. Faith was a hard topic to discuss with patients but there was some understanding of wider spiritual needs which emerged in discussion.
- Community involvement was very varied from having an active Friends group, to a nun who visited the ward and no contact at all.
- The findings were similar to the conclusions reached in the literature review.
- There was a lack of implementation of previous findings and inconsistencies in approach.
- Evident compassion from staff.
- Lack of knowledge and support in relation to the spiritual dimension.
- A desire to understand more and to have opportunities for learning.
- Lack of awareness of resources currently available and little opportunity provided in relation to training on spiritual care needs.
- Access to the chaplaincy service was valued for patients and staff.

Conclusion

- The educational resources are all in place but access to training in terms of time and resources and empowerment from management to enable their staff to professionally develop their roles is lacking.
- Some induction courses include spiritual care but none of the nurses could remember if this was included.
- A rounded educational package that is accessible for all HBCCC staff is required as a mandatory part of initial training and on-going CPD.

The presentation can be found www.fiop.org.uk

Thoughts and ideas emerging from the discussion

Strategic

- The importance of the person-centred approach the patient is at the centre of all discussion and partnership with health care professionals.
- Creating, developing, understanding relationships across all disciplines and valuing teamwork. Collaboration must be a key component.

"Developing relationships with colleagues in non-chaplaincy posts is key to communication and education about spiritual care" (Participant)

- Applying spiritual care to staff improving empathy
- Applying policy and practice to ensure consistency of understanding and approach
- Developing and implementing education at all levels including students with the involvement of the chaplaincy. Understanding how to fit such education into a total education package. This should include an induction package.
- Training must relate to an evidence based approach and inform it.
- Spiritual care must not be an add on but embedded in care as part of a
 compassionate approach with an understanding of the wide definition of spirituality
 as it embraces religion for some but other sources for others.

"It is difficult to raise awareness and legitimacy of spiritual care with staff in the NHS which doesn't 'promote' it more." (Participant)

- Learning how to generate conversations and particularly end of life matters.
- In using the 'What Matters to You' forms learn to elicit stories.

"What counts as hope?" (Participant)

"Learning to live with uncertainty as part of 'normal life'." (Participant)

Allow time for staff reflection

"One size doesn't fit all – know the context. Have a general but adaptable model." (Participant)

Branding

Redefine the term chaplain

"Street cred – what would this be?" (Participant)

• What does the role mean? Perhaps more important to educate people about the role rather than jettison the word. Important not to lose something distinctive about the role and then end up re-inventing the wheel. But important to know what is distinctive about the role.

"Recognise the pool of expertise in the chaplaincy." (Participant)

"What makes an expert? Consideration of education pathways into and through the profession." (Participant)

Need to tackle perceptions about chaplaincy.

"How do chaplains want to be seen?" (Participant)

- Could chaplains take on a role in anticipatory care planning?
- Making the chaplaincy and spiritual care more visible
- Is the chaplain considered to be part of the multi-disciplinary team?

Ideas for future events

- What changes have happened in spiritual care; what has improved patient feedback.
- Understanding spiritual care across disciplines, similarities and differences.
- Dementia, caring for carers and involve someone in advanced old age.
- Auditing outcomes in spiritual care.
- Addressing apathy or negativity regarding spiritual care.

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Spiritual healthcare has been the subject of debate in higher educational institutions and hospitals for many years and the Scottish Government Health Department (HDL (2002) 76) and following revision in (CEL (2008) 49) stated explicitly that spiritual care is integral to healthcare. It has also stated that all Health Service staff are spiritual care providers and guidance requires each Health Board to draw up a spiritual care policy which applies across the board area.

Health boards have an obligation to deliver spiritual care specifically considering key policy drivers from a range of health- related policies such as the Palliative Care Delivery Plan (Scottish Government Dec 2015). The need to ensure that spiritual care education is provided is encompassed in the guidance issued in 2008.

This strategy is in line with the original spiritual care document published by NES (2009) in which Levison noted that:

'Spiritual care in the NHS must be both inclusive and accepting of human difference. As we learn to listen better to the particular needs of different people, so we equip ourselves for work which is more fulfilling and effective. The provision of spiritual care by NHS staff is not yet another demand on their hard- pressed time. It is the very essence of their work and it enables and promotes healing in the fullest sense to all parties, both giver and receiver, of such care.'

However, spirituality **as a concept** is complex and there are many definitions which include:

"Health is not just the absence of disease, it is a state of physical, psychological, social and spiritual well-being" (World Health Organisation, Precis of discussion, 1948).

'Spirituality recognises the human need for ultimate meaning in life, whether this is fulfilled through a relationship with God or some sense of another, or whether some other sense of meaning becomes the guiding force within the individual's life. Human spirituality can also involve relationships with other people.' Mowat and O'Neill (2013)

The Nurse and writer Narayanasamy (1991) described the elements of spiritual need in the following terms:

"The need to give and receive love; the need to be understood; the need to be valued as a human being; the need for forgiveness, hope and trust; the need to explore beliefs and values; the need to express feelings honestly; the need to express faith or belief; the need to find meaning and purpose in life."

The pressure of time on hospital chaplains and on staff in the clinical setting means leaves little room for manoeuvre to enable staff to better encompass the spiritual dimension underpinning the person-centred approach to patient care.

A Scottish health board chaplaincy unit and Faith in Older People, a voluntary organisation, collaborated to undertake a small study in nine Hospital Based complex clinical care (HBCCC) units looking at the perceived definition of spiritual care and its delivery at the point of need. The conclusion of the study was that the definition of spiritual care was largely unknown and, while often instinctively delivered, had no sense of cohesiveness and structure in its delivery. Education in spiritual care was found to be inconsistent and not always accessible. There was also a lack of awareness of the availability of education and priority was given to the day to day clinical tasking, taking precedence over the personcentred approach.

The four themes identified through the literature review were similarly recognized during the iterative process of analysing data. Broadly examined the four areas were divided up into the following and from these main themes, subthemes emerged:

- Time community connections; evolving relationships; spiritual loneliness; practice based learning; tasks which cause a conflict
- Person centred care and the perceptual understanding of this by staff belief; faith and religion; well- being; perceptional barriers; comfort
- Spiritual care education insufficient; staff support required for education; confidentiality; previous training; Lack of activities; need to identify resources including financial.
- Community involvement present delivery of spiritual care; effective staff input systems; voluntary input; staff delivery; receiving of spiritual care; relative needs; ineffective staff support

How did the participants understand spiritual care?

Basically religion. Important at times of needs when someone might need extra support to build resilience and to provide a sense of hope. He did not feel that many of the patients acknowledge a faith or ask for a chaplain or minister.

I am a newly appointed activities coordinator for the HCCC unit but not yet taken up my post. What the patient beliefs are is important, trying to help them worship, go to church. I feel that spiritual care is faith/religion and I need to help them practice that belief though I am not religious myself.

A person is divided into body, mind (consciousness) and spirit – it's about connections for the person including beliefs and faith and what makes the person who they are. It connects the body with your soul, your creator, with what makes the person who they are.

Time

Nearly all the interviews focussed on the time constraints causing conflict with the care that the health carers wanted to give. Ironically it became quite apparent during the study that as the interviewers gave space for the staff to reflect they became increasingly positive about the concept of spiritual care and their own interpretation of what this could mean to their units in the future.

The emerging sub themes focused on the lack of time for the whole multidisciplinary team, not just the ward staff. Education was given a lesser priority and community involvement was reduced because of the lack of time to facilitate the nurturing of relationships and the administrative infrastructure to support additional services

Depending on what they say it is about a quick reaction (from me) sometimes I haven't done enough to address what they ask for instance, if they say they don't want to be a bother I miss the opportunity to speak and ask them what they mean. But I don't have enough time.

Person-Centred Care

The soft issues of spiritual care became more apparent during the interviews which gave credence to the difficulty researchers have with defining spiritual care. Different levels of perceived understanding of person centred care emerged when talking to managers and health care assistants. Managers appear to regard it as a clinical/task issue articulating the process well, whereas HCAs understood and delivered the process of giving spiritual care but were unable to articulate it as **spiritual care**.

When someone passes away though I always speak to the person while I am seeing to them (laying them out) and I always keep the window open to let their spirit go. I think that is so important. While they are alive we should treat them individually and help them see

themselves. I try and build up a trust with the patient and relate to them. I try to personalise their home and not just let the room be a bed and four walls.

Until going to University I had only thought of spiritual care as meaning religion. But now I understand that is broader and depends on what each patient wants and what provides 'comfort' – or spiritual comfort and this means ensuring that there is enough time for each person to understand what it is important to them; what they have done or were like in the past holding their hand.

Educational needs

Almost all the literature reviewed for this study found a lack of educational resources and training for staff. Levison (2005), who was central to the development of spiritual care guidelines from its inception as a philosophy for care, said that training health care professionals in spiritual care should be an integral part of health education. Indeed, the RCN survey (McSherry 2010) across the UK showed that 79.3% of nurses from the survey agreed that they did not receive sufficient education and training in matters concerning spirituality and felt inadequately prepared to deal with spiritual concerns.

Two basic recommendations for education emerged from this literature review. Firstly, that it is knowledge and understanding of the belief system; culture; traditions and preference of the individual (Wynne 2013; Byrne 2008) and secondly a tacit understanding of how to implement that knowledge in a clinical situation (Kevern et al 2013; Pulchalski et al 2014). Not only is there a need to deliver appropriate education **to the healthcare staff**, there is a requirement from management staff to be committed to its prioritisation within the health service (Walters and Fisher 2010).

McSherry's 2010 survey for the RCN recommended that spirituality should not be segregated to its own subject, which relegates a single subject to motivated parties, but rather be part of **person centred practice**.

During the interviews conducted in each of the HBCCC, the nurses quite frequently examined their understanding of spiritual care and began questioning how they had delivered it and whether they would change their practice in the future. There was evidence that the interview itself produced a cathartic response and reflection. i.e. the nurse who went and looked at what was available in the community and then emailed us to tell us what she had found, having never thought of doing this before the interview.

Perceiving spiritual care as religion seemed to be a structure enabling people to feel secure, but it wasn't clear whether it was the patients that felt secure or the staff (who described spiritual care as religion) rather than something much wider. Most of the staff who described spiritual care as religion then went onto reflect about other elements. There was also an external response to spiritual needs i.e. calling in the minister to deal with perhaps difficult conversations about death and dying which many of the nurses admitted not feeling confident to deal with this, particularly when they did not have the support from chaplaincy

that they needed. When they did have this support, they felt much more empowered in their roles.

Among the basic spiritual needs that might be addressed within the normal, daily activity of healthcare are (Koenig, 1994):

- to give and receive love
- to be understood
- to be valued as a human being
- for forgiveness
- for hope and trust
- to explore beliefs and values
- to express feelings honestly
- to find meaning and purpose in life

The interviewees were asked to arrange these basic spiritual needs in the order of importance from the point of view of the patient. It was recognised that preparing for death and dying was the lowest collated rating and the one person who voted for this as first preference was a manager. The focus that the staff chose as being their perceived top priority for the patients was personal dignity and a sense of worth. Whereas meaning, purpose and hope was given a lesser priority. In these basic concepts of compassionate care, none of them are clinical, but can be expressed while carrying out the clinical tasks necessary to physical needs of the patient.

A similar study was undertaken in care homes (Welsh, 2015).

Community Involvement

Three fifths of the interviewees said that they had community involvement in their units while the rest said that they had no community engagement at all.

There was in each unit a recognition that team work acted as the basis for staff support and safe evidence based patient care and that the team was much wider than the NHS staff on the ward. Community involvement supported the regular staff not only in social activities but also in the emotional attachment that is inevitable in units which are family orientated. Sometimes the community help is not always as helpful as it could be:

There used to be a visitor who brought in a dog which the patients loved but she doesn't come any more. The same applied to music but there is a view that the patients are too frail to enjoy these things.

There used to be a service here but it stopped because the patient group felt it was not needed. It was the decision of the minister not to come in anymore. Ministers felt that the patients didn't need it either.

The voluntary input of community care from various people such as priest, nuns; ministers or groups were all seen as positive resources. In fact, it did not seem to matter who they were, provided they were people who cared enough to give up time to support both patients and staff.

There aren't many volunteers on a regular basis but they are important as it is an opportunity to give patients specific time.

One unit manager realised the extent to which volunteers could be a significant addition to the team and allotted funds to attract external groups.

There was a sense of frustrated resignation at the need to provide spiritual care but being unable to grasp at faint possibilities because of barriers from time, accessibility and the external decisions made by those other than the patients or staff.

Churches only come to the home if requested by an individual but (I feel) that being able to talk about 'faith' for some people was important and there is a need.

Sometimes a priest or minister comes but this is dependent on the families. Other wards where there are higher functioning patients' activities are offered. Because of the capacity of the patients in this ward it is difficult to design activities except on a one to one basis occasionally. Hand massage is enjoyed.

The provision or not of community involvement highlighted the vast differences to be seen within one very small geographical area. It was evident that all five groups, chaplaincy, community, patients, relatives and staff wanted to take advantage of these resources in varying degrees but were unable to do so due to lack of finances; time; knowledge or inability to gauge the appropriateness within the unit.

A similar study has recently been published identifying current skills, training needs and recommendations for end of life emotional, psychological and spiritual care in the independent sector (2017). This study drew from a wide geographical area across Scotland to represent a spread of experience using four focus groups with a 50- member participant. The recommendations focused on end of life care guidelines specifically for care homes. However, embedded in the conclusions made was a recognition that staff need training to 'get better at talking about dying'. Front line care workers have little recognition in terms of the education that they need to carry out a wide breadth of understanding in end of life care. Sufficient investment to support the training needs would enable and empower managers to implement the recommendations that have been long in the making. Scottish Care (2017) has identified key findings in their study on the much-needed support required by staff to prevent fatigue and stress outcomes.

This study conducted in the hospital based units has found similar outcomes to the Scottish Care (2017) study which was focusing on the independent sector.

Conclusion

Spiritual enrichment is enabled through understanding the patient narrative and the stronger that link the more enriching the experience, not just by the individual but by the whole unit family.

Recommendations

- Develop an understanding that enabling spiritual needs to be met is everyone's job
- To increase education on spiritual needs for all clinical and allied staff with a rounded educational package that is accessible and is a mandatory part of initial training, induction and on-going CPD
- To ensure that agreed spiritual care policy is implemented through health care systems
- To ensure that all health staff are aware of the current educational resources on spiritual care
- To value and encourage contact with the spiritual care teams as part of the multidisciplinary team
- To ensure that there is information about local community resources which can be called upon
- Work with relatives and friends to build a picture of 'what matters' to the patient (Digital Passports PAMIS) and to participate in anticipatory care planning
- Aim to achieve a balance between clinical tasks and 'being with' patients to create a stronger awareness of when and how to engage with 'critical conversations'
- Supporting staff to understand their own spiritual care needs in the light of providing care at the end of life

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