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

A collaborative study between Faith in Older People and NHS Lothian Spiritual Care

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Abstract

Spiritual care has been the subject of debate in the health sector for many years. The Scottish Government (2009) stated explicitly in its report on developing spiritual care within NHS Scotland that this is integral to healthcare, commending the work which had implemented the previous policies drawn up by the Scottish Executive Health Department (SEHD 2002). Spiritual care is necessary for person-centred care and is therefore an integral part of healthcare, based on the Scotland's House of Care model (2014). Health boards have an obligation to deliver spiritual care considering a range of health-related policies such as the palliative care delivery plan (Scottish Government 2015). The SEHD (2002) recognises that spiritual care teams are a vital link in providing specialist input in situations of long- term care, resourcing healthcare staff, and facilitating and delivering spiritual care directly to patients, their visitors and staff. Given the nature of increasingly dependent multi complex patients it is clear that the need for spiritual care education of health staff is becoming more acute.

NHS Lothian Spiritual Care 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 rarely accessible together with a lack of awareness of the availability of education and resources.

During the study the emerging theme was that of the need to make education more accessible using existing resources recognising that although previous recommendations still applied to the spiritual needs of older people they had not been implemented in practice.

From the evidence this study seeks to make recommendations for the sustainable delivery of education in spiritual care to all staff in HBCCC units which should be embedded in their professional development plans.

Aim of the study:

The aim of this study is to examine the perception of spiritual care, in terms of spiritual needs assessment and facilitating and delivering spiritual care among staff working in HBCCC units. This examination includes a review of available resources for education in spiritual care and a review of participants' learning needs.

Objectives:

- To search existing literature on spiritual care relating to Hospital Based Complex Clinical Care (HBCCC) units.
- To interview staff in the nine NHS Lothian HBCCC units as to their perception and understanding of the spiritual needs of residents and how these spiritual needs can be effectively identified and responded to by improved education and support of NHS staff.

Background

The idea for this study arose out of anecdotal concerns from NHS staff to a member of the spiritual care team in one HBCCC identifying gaps in staff knowledge to support the spiritual care needs of their residents. The spiritual care team in NHS Lothian where this study took place was concerned about the need for spiritual care in HBCCC units and their lack of capacity to provide it according to the guidelines. They approached Faith in Older People to ask if they would collaborate on a scoping exercise to examine and identify knowledge and understanding required by health care staff to deliver spiritual care.

A previous study (Welsh, 2015) examined the perception of independent care home staff towards their understanding of the concept of spiritual care concluding more work was required to support their education. It was recognised that this present study would develop these findings with specific reference to HBCC units and provide recommendations to stake holders, supporting the development and implementation of education and training of spiritual care to those staff working in HBCC units. There was also recognition from the NHS Lothian Spiritual Care that, alongside NHS chaplains allied health professionals and representatives from faith communities and other voluntary organisations could be encouraged to take part in responding to identified spiritual needs of patients within the HBCCC setting. The definition of a hospital chaplain takes various forms. Baldacchino (2015) describes a Hospital Chaplain as one who is an expert in Clinical Pastoral Education and who can give help with theological beliefs and conflicts but may also go under the title of Pastor. Others (Barber and Parkes 2015) describe the Spiritual Care Team or the Chaplaincy team as a necessary member of the health service for the wellbeing of mental health. It seems therefore, that there is no one title for the group of professionals who care for the spiritual dimension of health care.

HBCCC units are defined by the nature of the care that is delivered using robust guidelines (Hospital Based Complex Clinical Care Units HDL (2015) 11, 28 May 2015) which is intended to make the clinical decision more transparent using the primary eligibility question:

'Can this individual's care needs be properly met in any setting other than a hospital? The outcome of this question is discussed, documented and explained fully with individuals, families and carers.'

A review of the literature revealed a plethora of spiritual care definitions. This Scottish study adopts Mowat and O'Neill's (2013) definition of spirituality:

'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.'

This is the underpinning philosophy of healthcare that supports and nurtures the spiritual life of patients, and staff. NES (2009) describes this as the:

' *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 prayers or sacrament, or simply for a sensitive listener.'*

Patients in HBCCC have multiple challenges with long term conditions, palliative or end of life care and are usually placed in these units for the duration of their lives. The challenge for the staff of the units is to ensure that the people who become patients in their care have a

quality of life that is better than that which they would have received in their own home, given the complexities of care which necessitated their admission to the unit. This study explores the significance and potential benefits of integrating spiritual care into person centred care, rather than understanding spiritual care as an 'add on' to the necessary physical care required by people who can no longer care for themselves (Wallace 2011). Wallace (2011) maintains that 'spiritual wellbeing leads to a better quality of life' regardless of faith or no faith, because religion does not necessarily mean spirituality.

Ahmedzai (2017) also states that good end of life care goes beyond the distressing symptoms of physical degeneration. It must also include the eliciting of information about spiritual, cultural, religious and social preferences to deliver individualised care.

In the SEHD HDL (2002) report it was recommended that the NHS provide healthcare chaplaincy services at the rate of one session for every 25-30 beds and spiritual care education for all NHS staff ensuring that it is part of their professional development. At this time it was recognised that those most likely to facilitate education would be those with the most appropriate knowledge - the existing spiritual care teams. In 2009, the Scottish Government widened the scope of spiritual care to the promotion of research which broadened and enlightened the evidence base for the efficacy of spiritual and religious care in health. Since August 2017 the UKBHC's (United Kingdom Board of Healthcare Chaplaincy) register of healthcare chaplains is now accredited by the Professional Standards Authority.

Following the recommendations from SEHD 2002, Health Improvement Scotland undertook a scoping exercise examining spiritual care in the NHS (2005). Subsequently, the Scottish Government (2008) provided revised guidance on spiritual care in the NHS, requiring all health boards to provide a 24hr chaplaincy service. It was made clear that spiritual care was

person centred; included but not exclusive to, religious care, demonstrating that 'people are not merely physical bodies requiring mechanical fixing.' Given this emphasis it is surprising that although documents such as Scottish Government's Strategic Framework on Palliative and End of Life Care (2015) mention spiritual care in principle little attention is paid to the need to support staff education in this area. This is despite the WHO (2017) definition of palliative care which clearly emphasises the inclusion of spiritual care.

Spiritual Care teams have been on the decrease in most health boards over the past ten years (Kelly 2012) although anecdotally the overall compliment within teams has remained static. Given the challenges faced by the NHS the position of Spiritual Care is remarkably healthy. However, while legal requirements have ensured the minimum patient: staff ratio levels in the clinical setting there is no room for manoeuvre to enable staff to develop the spiritual dimension underpinning the person centred approach to patient care.

In addition to the Scottish framework for spiritual care the national guidelines (NICE 2013) state that all persons requiring end of life care should 'offer, facilitate and provide spiritual and religious support.' The SIGN guidelines for control of pain in adults with cancer advise that 'service providers and those providing education should have a basic understanding of the range of beliefs held by patients across a multifaith and multicultural context. Also, that support should be provided for professionals in dealing with the impact of their work on their own understanding of themselves and their belief systems (SIGN 2008). Despite these national guidelines the End of Life Care Audit for England (2017) documented the vast discrepancy between trusts as to the staff/patient/relative discussion regarding their spiritual, cultural, religious needs. This ranged from <20-100% of discussions with a national average of 42%. However, it seemed that once the discussion had taken place in 89% of the cases the needs were met.

The Royal College of Nursing (RCN) has also recognised the importance of spiritual care and after a lengthy scoping exercise (2010), receiving the largest response than any other survey the RCN had undertaken, developed a short guide to spiritual care (2010) and a tool for nurses to use in assessment of spiritual care needs.

The SEHD HDL (2002: 48,49) guidelines recommended that all NHS staff be trained to assess the spiritual needs of their patients in order that over reliance would not be placed upon the spiritual care services. 'This should be a normal part of professional development for all clinical and non-clinical staff involved in patient care.' The Scottish Government (2008) guidance subsequently ensured sustainability for spiritual care education within the NHS by placing staff training and the chaplaincy training and development unit within NHS Education for Scotland (NES). NES has embedded in their 2016-17 local delivery plans a commitment to education for staff in reflective practice to support the delivery of bereavement care and staff wellbeing; values based reflective practice and emotional matters in line with the Palliative and End of Life Care Strategic Framework from the Scottish government (2015). 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.'

Despite the national guidelines and the plethora of research and studies examining the evidence and need for spiritual care, it still seems that there is a gap between recommendations and implementation. It is hoped that by identifying the results of this study within the practical setting of nine HBCCC units, a consistent approach to both development and implementation of education in spiritual care would be offered. The authors of this paper consulted with several stakeholders to ensure that they had a robust aim and that the results would be transferable across Scotland and perhaps wider. These included representations

from NHS Education for Scotland; Edinburgh University School of Health and Social Science and members of the spiritual care team in NHS Lothian.

Methodology

It was felt that appreciative inquiry was the most suitable methodological approach for this exploration of spiritual care needs assessment and the delivery of spiritual care in nine HBCC units within NHS Lothian. The ethos of appreciative inquiry corresponds to the values of spiritual care. For example, appreciative inquiry involves asking questions that look for the best in people and the most positive lived values demonstrating constructive and visionary futures (Cooperider, D. Whitney 1998) based on 'helping us to discover what could be rather than trying to fix what is' (Bushe 2013). A qualitative approach, which emphasises inductive reasoning (Newell, Burnard 2006) investigated personal and lived experiences using open ended questions in a piloted questionnaire. Open ended questions were used to encourage reflective responses from participants. At the outset of the study the researchers elected to use a modified version of Koenig's table (1994) asking the carers to put in order concepts such as forgiveness; preparation for death and dying and a feeling of being loved. These questions were asked of the carer rather than Koenig's original questioning of the cared for and so possibly had a different bias on the understanding of how the carer answered. Some answered on behalf of their patients and others answered in relation to their own feelings. While this produced a lack of comparability in the results it did give permission to further reflection on the part of the participants.

The results are shown in appendix iii and were reflected in the wording and themes of the questionnaire. The authors followed a rigorous iterative process of discussion and coding the collected data, dividing into themes and subthemes. Conclusions and recommendations were based on the results of the data outcomes.

Literature Review

The literature search was carried out by the library of the Royal College of Nursing (Edinburgh). This review (appendix ii) examined articles based on the subject of spiritual care amongst older people in small long-term care units in UK. The British Nursing Index, CINAHL and web resources were searched, and 32 appropriate items were found, of which 16 were reviewed for the purposes of this study. The criteria required was papers in English from 2000; using the words spiritual care; health care and spirituality; person centred care and spiritual care; spiritual care and education; hospital based spiritual care and end of lifecare. The review discovered four common themes running through the literature and was able to place the current study in context (Newell and Burnard 2006). There was a constant interlinking between all the themes which directly reflected the comments made by the interviewees and was not formally recognised until the data had been analysed and notated.

The four themes noted in the literature search were individual narrative**;** person centred care; educational needs and community involvement.

Individual narrative

Barbour (2013) noted the primary importance of individual narrative elicited through skilled questioning. The essence of a person is to be found within their own story which cannot be separated from their spirituality (Byrne 2008; Barbour 2013). Intentional listening builds resident identity and allows spontaneous connections (Barbour 2013; Higgins 2013) which in turn inform the use of appropriate tools and social activities. Kevern et al (2013) discussed a certain reluctance of staff to explore the issues of spirituality within a health care setting instead focusing on the clinical aspect of caring.

Person centred care

Spirituality is the third part of the triangle of wholeness comprising body, soul and spirit (Barbour 2013) but requires flexibility from care staff to allow the individual to flourish (Byrne 2008). Paley (2008) observes that there needs to be a move away from 'nursification' of spiritual care and towards an understanding of individual needs. The UK Board of Healthcare Chaplaincy (2015) defined the role of a band 5 training chaplain (http://www.ksf.scot.nhs.uk/understanding-ksf-dimension) as someone who assesses the spiritual and religious needs of patients, visitors and staff, seeking to meet those needs or refer on. Conversely Puchalski et al (2014) would want to operationalize spiritual care stating that 'compassion should be the driving outcome for any health care system.'

However, Scotland's House of Care (2017) has brought the operational systems of various agencies together with the principles of care, support and enablement to provide the desired whole person care. Spiritual care, as the foundation of a person's individual need to be listened to and understood, fits into the warp and weft of the house of care, although is not explicit in any of the documentation (Alliance Scotland 2017).

The use of spiritual care assessment tools can be an aid in offering person centred care to the individual. There is a plethora of tools available for various settings and disciplines. The tool FACT (La Rocca-Pitts 2012), faith, availability, coping and treatment, is used in the acute setting by chaplains and explores five areas of spirituality as present narrative rather than history taking. FICA, (1996 faith and belief; importance, community; address in care) on the other hand, is a spiritual history tool developed by Puchalski et al (1996) which can be used in all health care settings. Four themes on a handy card can produce a wealth of information from the patient, setting the scene for individualised care. The HOPE questions (Puchalski 1999) develop the spiritual theme within the FICA tool. Some tools such as the Touro Institute spiritual assessment, essentially a training guide, can only be used for those with a personal belief in God. Power (2006) argues that sensitivity is required when using

any form of spiritual assessment tool due to the vulnerability of the patient setting and the relationship that is required prior to asking such intrusive questions. It may be more appropriate for clinical settings to have a choice of tools that can be patient specific.

Educational needs

Almost all the literature reviewed for this study found a lack in take up 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 in Scotland, said that training health care professionals in spiritual care should be an integral part of health education. However, the RCN survey (McSherry 2010) showed that 79.3% of respondents agreed that they did not receive sufficient education and training in matters concerning spirituality and felt inadequately prepared to deal with spiritual concerns in patients. Vivat (2013) agrees with Levison (2005) and calls for theory to be translated into practice.

Two basic recommendations for education emerged from this literature review. Firstly, learning requires to be knowledge based in terms 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 with compassion and understanding (Kevern et al 2008; Puchalski et al 2014). Not only is there a need to deliver appropriate education, there is a requirement for management staff to be committed to its prioritisation and crucially, implementation within the health service (Walters and Fisher 2010).

As a message to the educational establishments delivering spiritual care, McSherry (2010) recommended that spirituality should not be segregated to its own subject, which relegates a single subject to motivated parties, but rather be a necessary component of person centred practice.

Community Involvement

The information on community involvement varied widely from recognising the paucity of community chaplaincy teams (Barber 2013) and so using links with local churches (Higgins 2013) while being transparent about the possibility of proselytising, to a complete lack of equity available in a service which appears geographically fragmented (Levison 2005). While Paley (2008) calls for hospital chaplaincy to extend its operations beyond the present 90% Christian laity, Vivat (2013) discusses the shift in providing spiritual care from religious professionals to health and social care providers. This paper describes the decline in religious beliefs since 2001 and therefore the need for a consistent approach to implementation of national policies given the ethnic diversity now present in the UK. But without clarity on the definition of spiritual care, it is a challenge to describe the providers of what appears to be a much needed, yet avoided, service. Walters and Fisher (2010) would welcome greater spiritual input from the community but failed to clarify either provider or provision. There is, however, acknowledgment that the voluntary sector could and does play a significant role in supporting the spiritual care needs of patients and residents given the decline in religion and an increased interest in secularization highlighted by Nolan (2011).

A similar study to this has been developed by Scottish Care (2017) identifying current skills, training needs and recommendations for end of life emotional, psychological and spiritual care in the independent sector. This study drew from a wide geographical area across Scotland representing a spread of experience using four focus groups with a 50- member participant. While the recommendations focused on end of life care guidelines in care homes, there was recognition that staff require training to ‘get better at talking about dying’.

There is little recognition in the education of front- line care workers that they need to have a wide breadth of understanding in end of life care. There needs to be sufficient investment to support the training needs which would enable and empower managers to implement the recommendations that have been long in the making. Scottish Care (2017) identified key findings in their study on the much- needed spiritual care support required by staff to prevent their fatigue and stress outcomes.

Method and findings

This study conducted in the hospital- based units has found similar outcomes to the Scottish Care (2017) study which focused on the independent care sector. Levison's (2005) clear imperative to care for all faiths and no faith encapsulates person centred practice, giving this study a robust focus for promoting the implementation of previous recommendations.

The qualitative approach emphasises inductive reasoning (Newell, Burnard 2006) investigating personal experiences. The authors followed this positive line of inquiry through open ended questions directed at the nursing teams in each of the nine HBCCC units. Twenty- nine people were interviewed including the pilot questionnaire which was conducted in an independent care home used in the previous study by Welsh (2015). The pilot was not carried out in an HBCCC unit because of the difficulties experienced in arranging interviews. The experienced interviewee from the pilot gave the team an indication of the direction of questions and the questionnaire was altered accordingly.

The questionnaire (app i) was based on previous research experience from the authors; anecdotal evidence from the local spiritual care team and the literature search. The questions were divided into four main themes:

1. Information regarding the patient from the time of admission.
2. Assessment of patient priorities and staff response.
3. Identification of previous education and present knowledge and understanding of spiritual care.
4. Community or other involvement which was recognised as spiritual care.

Although person centred practice uses the term ‘person’, it was noted that in all the HBCCC units that were visited residents were always referred to as ‘patients’. As McCormack (2003) observes there is a distinct crossover between the practice of being person centred and the name given to people in the hospital setting, which should not detract from the rights of individuals as people.

The intention of the authors was to interview three staff members from each HBCCC unit who were of different nurse levels in order to gather a depth of material which would inform the iterative process of data analysis. Ideally the three levels would consist of a nurse manager/staff nurse; a health care support worker and a social activities coordinator (SAC). The inclusion of an activities coordinator was based on the fact that it is desirable for all care homes to have an activity coordinator in order to ensure the holistic well-being of residents and to fulfill the National Care Standards. The reality in the HBCCCs was that this was not the case and the authors only found one SAC in all nine units. Consequently, most of the interviews were with health care support workers, many of whom took on the role of a SAC within their daily routine.

The interviews were conducted in the HBCCC units with the signed permission of the previously contacted manager. This was a purposive sample with recommended interviewees by the managers, however as they often were not free because of the constraints of duty of care there was inevitable snowball sampling as they recommended other members of the team. Each interviewee signed a consent form agreeing the use of anonymised information in the study. During the questionnaire (app i) the authors used one stimulus, based on Koenig’s (1994) 14 spiritual needs of older people, modified by Gibbon and O’Neill, for the purposes of a workshop held in Dundee (2015) enabling interviewees to reflect on their perception of prioritising spiritual care.

The iterative process of analysing the data collected was conducted over a period of some weeks through discussion to identify themes and sub themes. These were then coded and anonymised recognising emerging new concepts and consistent commonalities from each of the units.

Limitations :

Due to unforeseen circumstances the interviews were not all conducted by the same researcher causing possible data bias. There were many constraints due to the part time nature of the authors and therefore the project took longer than the original time framework. This may have resulted in better quality interviewing because the interviewers took longer at each data gathering or conversely the data gathering could have been fragmented as interviews often had to be cancelled at short notice.

Although the original aim had been to interview a SAC in each HBCCC unit, only one SAC was interviewed as there were no others employed at that time. The pilot interview with a SAC however, gave constructive comments on the basis of which the questionnaire was edited.

Ethical approval

The Research and Development Department at the Health Board was approached to ask if we needed formal ethical approval for the study. This was not required but the authors were advised to ask for approval from the Quality Improvement Team and register the project in order to meet with data protection issues. The project was formally registered with the caveat that digital recording was not used due to various confidentiality issues.

Funding

The project was jointly funded by the Spiritual Care Department and Faith in Older People. This allowed basic research costs to be covered along with administrative expenses.

Interpretation of findings

As the authors visited the HBCCC units the overriding impression was one of positivity in caring for patients often in challenging circumstances with limited resources. Innovation and the timely use of existing assets were essential to quality caring. The comments made by interviewees were similar regardless of whether they were at management level or a health care support worker.

Thematic analysis of data gathered identified similar findings to those detailed in from the literature. Broadly examined the four areas were divided up into the following and from these main themes emergent subthemes were recognized which will be discussed at length in the next section:

1. Time – the timely use of community connections; evolving relationships; spiritual loneliness; practice- based learning; tasks which cause a conflict through the nature of the time they took to perform.

2. Person centred care and the perceptual understanding of spirituality by staff – what was meant by belief; faith and religion; wellbeing; perceptional barriers; comfort.

3. Spiritual care education – nurses feeling incompetent in their knowledge of spiritual care; the staff support required for education; confidentiality; previous training; lack of activities; identification of practical and educational that were available.; financial resources.

4. Community involvement – present, past and future involvement on the HBCCC units; effective staff input systems; voluntary input; relative's needs; effective or ineffective staff support from community.

1. Time

Most interviews reflected on time constraints causing conflict with the care that the health carers wanted to deliver. 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 them and their units in the future.

N10 *"Am so on board with this project and would love to be a pilot if that were possible for spiritual care in the ward."*

One charge nurse was so enthusiastic about changing her outlook from having no time for implementing spiritual care that she went away after the interview and found out about existing resources, emailing to say thank you for giving her the stimulus to reflect on what could be implemented. The healthcare assistants (HCA) also discussed their need for time required to nurture relationships and give quality time to the patients. They recognised that without that stimulation boredom, loneliness and non-engagement could so easily affect the quality of life not only of the individual but also of the ward community. One particular HCA stated that the intervention required need not be of any academic quality or skill, just the ability, and time, to hold a hand. It was recognised by the staff that volunteers could have a significant part to play when engaging and nurturing patient relationships.

H25" *There aren't many volunteers on a regular basis, but they are important as it is an opportunity to give patients specific time. Even someone to hold their (the patient's) hand would be good"*

The questions asked on initial assessment focused around the patient narrative and the importance of giving time to allow that narrative to be as rich and informative as possible. Because it takes time to form a patient story the nurses wanted as many members as possible to take part in this story building including family, who were able to contribute to managing time:

N6 Family members might contribute as they play a big part in the assessment, particularly if the hospital is to be the 'final place'

Optimising the use of various types of 'time' enabled this story to live and breathe. Types of time might be described as clinical or personal tasks such as bathing; dressing and wound management. During these times, evolving relationships are taking place, enabling special moments to develop the knowledge on which to base person centred care. It seemed that as the narrative widened of personal history, so the anonymity of the person disappears:

N6 it has to be opportunistic, general conversation – like when someone is unpacking. We can identify this at the initial assessment – I might notice distress and will talk at the time, then follow it up in another later conversation.

Opportunistic or incidental conversation is an evolving skill, as is an understanding that a lack of time does not necessarily mean a lack of spiritual care. Admission is the first opportunity to begin the narrative which may take many weeks to build up into a picture of instinctive understanding between patient and health care professional. One HCA said that she was 'nosey' but needed to feel the reality of patients' lives in order to make sense of the world in which she worked:

H19 I encourage them to be a part – gain their confidence. Someone died in my arms when he pressed the buzzer. He was afraid to die, and I said to him 'come I'll give you a cuddle' and he died. These people have had lives – just like mine. I hate seeing their possessions all done up in a bag. I love their stories because it makes them real. If you find out about their occupations, you can talk to them about it.

*T*here was also a recognition that missed opportunities due to lack of time might not give such a rounded picture of the patient as might have otherwise been:

N5 *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.*

There are ample assessment tools to use on admission, but they do not replace the 'conversation at the sink', where a patient is fulfilling a normal everyday function during which time they feel safe disclosing information that is key to care. One volunteer (S14) told us that she speaks to the patients in a 'normal' way and talks about her own life in an effort to get them to speak about their own. She tries to find out about their background, family and the work they used to do which demonstrated the importance of reciprocity and confidence building in order to find out the narrative. This appeared to be a necessary skill for teams working in HBCCC units.

Clinical tasks took priority as a matter of necessity, but it was apparent that the staff felt more was needed in order to lessen the institutionalisation of the units. Spiritual care seemed to improve clinical outcomes, which though important and necessary were given added impetus with the addition of compassion, kindness and that sense of family which the staff tried to create:

4b N6 we do everything ourselves. The staff are amazing. For instance, we have celebrated the Royal wedding, made hats for the ladies. Christmas is the focal point of every year, we put on a party and the staff does a show and we have a ceilidh. If staff have time they do something social – perhaps with something on the television. We try to get the men into the sitting room when there is football or a sweep with the Grand National.

Prioritising and differentiating between clinical tasks and spiritual care seemed to cause challenges when defining the difference. When asked what was meant by spiritual care most of the staff struggled to find a definition.

Without a clearer understanding and knowledge of spiritual care, the staff found it difficult to deliver what they perceived to be two different tasks – clinical and spiritual. One manager said that clinical needs were always the default which meant that spiritual needs were ignored as a consequence.

2a N10 [T_T] As a leader of the team I ask them to provide person centred care – I know it and believe it, but we don't have enough staff to carry this out and to provide what is needed. We do the things that the patient wants to do but this is a 30 bedded unit and very busy.

N5 We never get staff breaks as there are only two of us so not enough time. We offer no spiritual care/religion – too busy tasking. We are too busy responding so there is no proactive thinking. We do not even have time to get to know our patients.

Time management is a learnt skill. However, it must be noted that even given time to be with the patient may not be the right moment for the patient to engage.

S17 Each patient has a personal preference, but staff have to take account of all patients and the need to conform to a bigger routine and have to be aware of how to manage time effectively. There is an inevitable tension between this and the need to spend time with individuals. … We need to spend time with patients when they want to chat, not only when you want to or when you have time to.

Spiritual loneliness was identified by staff as a different concept to social isolation appearing as a result of the need for questions to be answered rather than the enforced loneliness that comes as a result of being apart from other people – whether chosen or not.

S17 some people like to be on their own. It is a big transition.....We have to make sure they are not feeling lonely or isolated...if they have anything they would like to talk about – if they are frightened. Patients with COPD for instance, they have night terrors and they often think they are alone.

The staff identified the risk of patients feeling lonely and isolated but also described the sense of spiritual loneliness which they felt was quite distinct. This has been variously described but the approach adopted by James Leonard Park (2017) encapsulates this deep sense of isolation arising from what he calls incompleteness in the depth of our being.

There appeared to be challenges for some patients who either wanted or were given single rooms as they felt cut off from ward activities and this increased their sense of isolation:

H22 The single rooms don't help the staff as time is against us. There is a sense of isolation and abandonment in the single rooms, when some already feel they have been abandoned. They have all day to dwell on a sharp or challenging word and are just on their own thinking

about it and nothing else. It is easy for the staff to become institutionalized – it is not just a job, there are not just pads to be changed, we need to be respectful.

Time was of the essence not only for patients but also for the staff when they needed to update their continued professional development. Practice based learning is examined in the chapter for education but there was a crossover with the implications for time. Commitment of time from managers was implicit in conversation although all the staff were protective of their immediate managers and did not feel that they were responsible for their perceived lack of education.

N2 Well at present we have to do all our learning at home – so we do learnpro at home as there is not enough time while we are on duty. Also, if someone is on the computer doing their learnpro then no one else can go and use the computer.

There appears to be a need to protect learning time, but there are no ground rules on how to actualize and implement that into the daily routine of patient care. Both leadership and management skills may enhance the ability to maximize the use of time to care.

When asked what difference education would make to their roles, many staff responded similarly.

N11 more job satisfaction. We do the best we can with what we have but often leave the shift feeling that there was more we could do. Basic needs are being met but not the soft stuff. It would make people feel more worthwhile if the patient needs were being addressed. We prioritise physical needs all the time – we have to.

Sub Conclusion for time

Across the interviews there was a feeling of how much more could be achieved with additional time available /allowed for each patient. Yet at the same time there was a sense of satisfaction at the innovation being used to utilise what little time there was available. Time is a resource that requires to be used to its optimum level within the priorities made by

staff. But there was also a risk of a cycle of diminishment which pervaded these conversations as staff and patients struggle against the dichotomy of time and conflict of care. The interviewers noted that rather than despondency there was a sense of acceptance at the lack of time to carry out caring and in some cases a lack of motivation to lift out of the 'what will be will be' mode. It was theorised that this lack of motivation came not from the staff but from the situation created through the passage of time and changes in imperatives set at national and local level.

The authors found that a disinclination to explore issues of spirituality arose not from an uncompassionate manner, but rather from a desire to ensure that clinical care was not compromised. The consequent effect on person centred practice was a reduction in time given to exploring personal non clinical needs.

2. Person centred care

The soft issues of spiritual care became more apparent during the interviews giving credence to the difficulty researchers have with defining spiritual care and staff perception of person centred care. Managers appear to regard it as a clinical/task issue articulating the process well, whereas HCAs understood and delivered spiritual care but were unable to articulate it.

N12 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. 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.

1a S17 [P_R+P_C+P_WB] until going to University I had only thought of spiritual care as meeting 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.

There appears to be a conflict as to what spiritual care can do for a person as opposed to what it means internally.

N11 For me it becomes more obvious when the patient is not well – i.e. physically or emotionally. If they are thinking about past things in their lives and they are trying to make meaning or if we are giving end of life care – we can offer a priest. But these things are all very external, aren't they? I think the thing that would benefit the patient the most is staff time – it is easy to refer and tick a box, but we need protected time to sit with the patient and just be with them.

There was some question in the beginning as to how service users were referred to in these units. As interviewers we were used to calling the patients residents or people, however, in these HBCCC units all the residents are referred to as patients. Generally, a patient is someone who has procedures done to them as opposed to a person who invites change in their lives. The questionnaire was based on spiritual care so while person centred care is a much more structured subject with a more defined outline, this study only addressed the spiritual care aspects of the person.

Perceiving spiritual care as religion seemed to be a structure enabling people to feel secure, but it was not clear whether it was the patients that felt secure or the staff (who mainly described spiritual care as religion). 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, particularly when they did not have the support from the Spiritual Care team that they felt needed. When they did have this support, they felt much more empowered in their roles.

S17 It would help the patient to have their needs met. It would increase my confidence particularly at end of life situations or when discussing difficult issues when some people do turn to faith. It is difficult to talk about faith but can encompass the wider spiritual care needs. We need support for these discussions especially if they are involving a specific religion.

Some of the interviews moved to the subject of death and dying due to the nature of the units, however, while there was an understanding that the patients admitted to the HBCCC

were there for the final period of their lives, and some perhaps only in the short term, it did not detract from the main theme of spiritual care regardless of their status.

N12 End of life care is about their religion – bringing in a priest etc. But if a patient was dying and wanted me to read something out of the Bible for instance I would do that.

This desire to know more about certain religions or beliefs showed that person centred practice was at the heart of the care given in the HBCCC but the ability to carry it out was dependent on additional knowledge and understanding.

H25 It would be really helpful to know more about religious ways or why certain things were important so that choices could be respected, whether of faith or not.

When it came to belief, this was more difficult to understand and comprehend. Belief went beyond religion which was much easier to grasp in terms of religious rituals. It was an internal concept often dependent on a personal world view with issues of the spirit rather than spiritual issues. In fact, the definition of the perception of spiritual care needs was varied:

H22 Actively engaging with spiritual belief of person. Most are of an age where their spirituality is private, so not often asked.

N4 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 creator, with what makes the person who they are.

N11 it goes beyond religious beliefs – looking at all aspects of their faith and even if they don't believe they can still be spiritual. But it is also about not neglecting those who are non-religious.

Just allowing the staff to reflect made a difference to their perception of spiritual care when providing a person centred approach which would enhance their practice.

N12 you have got me thinking because I haven't thought about it really until just now. I have categorised it into fulfilling someone's belief rather than being a part of their whole being.

2.1 Faith

Faith became a different discussion which centred not just on religion but included cultural understanding. Not on belief which is an internal understanding of personal world views, but rather on something external to the person which is internalised in order to help them cope with daily living.

N5 Addressing people's needs/anxieties/fears in a way that will put them at ease – support for them, filling a void. Religion is a dwindling area, but people put their faith in other things such as angels.

N1 It is not just about religion, it's about wellbeing inside, identifying what their wishes are: end of life wishes. As much as you are offering you are never going to meet their spirit needs, but you need to identify how they want to be treated.

2.2 Well Being

The staff referred to the sense of wellbeing that they wanted their patients to have while in their care and this seemed to take on two different aspects– internal and external. The narrative was the external discussion that then led to action on the part of the staff to fulfill an internal need for the patient. This internal need translated into finding a pathway through the present era in their lives which would possibly but not necessarily lead to a paradigm shift in any one of the components that made up their sense of wellbeing. i.e. rediscover faith, lose faith; routine; ritual.

Sometimes during the interview this became a highly charged issue of great import. One nurse said that she was worried that engaging with the patients on a spiritual level was so important that it almost became a safety issue with her but found herself prioritising clinical care at the expense of the inner wellbeing. Others felt that it was this kind of care that needed significant time spent on getting it right.

S17 having enough time is quite a challenge but whole person care is important. It is individual to every patient, so it can be about faith but not necessarily so. Can be beliefs but

it is person centred care as a whole and not focusing on their illness. Time is a challenge when delivering this kind of care

1a N6 [P_WB] It's about full well-being, not just religious but encompasses thoughts, feelings and ways of coping. A personal way of coping. It is not about religion but bigger than religion.

2.3 Perceptional barriers

Some of the staff admitted that there were barriers which prevented them offering that whole person care which included the lack of education and understanding along with lack of resources and time. Questions about spiritual care can be awkward and some staff cited cultural differences that can cause embarrassment and so need to be better understood. One of the questions on admission is to ask the religion of the patient which is fed into the NHS diversity audit. However, this question is rarely asked and consequently can affect the overall picture of Scottish diversity and culture.

N1 we just ask what religion – sometimes though they (the staff) don't ask because religion is a taboo subject in Scotland and also because of the frailty of the patient – religion is maybe not a priority at that moment in time. But often if the patient has come from another area (of the NHS) we still don't know what religion they are because they haven't been asked that question in the other place.

Not only does this cause a problem for the religion question but it can also be difficult when dealing with end of life issues.

H20 This is a very tricky area. It is sometimes possible to talk about 'end of life' matters and it is very important not to brush off questions if a patient raises them – should go with the moment. Example – 'I am still here today' response 'why did you think you might not be' etc. She feels that patients do have an inkling of what they are facing. The staff sometimes talk about what they are feeling in the face of these issues; perhaps at a team meeting or at handover time.

There is also a conflict between what the staff think the patient needs and perhaps what the patient actually needs.

H20 Ministers can be specifically invited by the family if he/she is willing. This is different for every patient. 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 particularly as the focus is on palliative care. However, patients are not always aware that they are dying or whether it is just part of shifting home.

2.4 Comfort

The issue of comfort was discussed on many occasions although the word was not used in the context of physical comfort but rather internal comfort - perhaps this could be best described as comfort of the soul. It was as if people could not necessarily express what the staff might have done for them, but they knew that as a result they felt more comfortable. Not only was this in the context of patient care but also concerning the support that staff received from each other. At the end of each interview staff were invited to add their own comments. One nurse proffered the fact that staff often feel isolated and not appreciated by senior management and it was made clear this was not their immediate managers. Frequently in the HBCCC staff were dealing with death and dying so when a patient died the staff also needed comfort which they generally received from their team.

Comfort to the patients meant something internal which gave them more than the settling of pillows and good pressure care.

H19 Some people have a religious background, and this is very important to them. There are other beliefs, so it is not just about religion but what 'makes you comfortable' particularly at the end of life.

N3 It is sometimes obvious for example if it is clear that religion is the key issue otherwise it would be looking at friends and other factors which provide comfort....*but it is whatever (emphasis) provides comfort to that person.*

4c N12 I would like it to be a priority. 'Myself as manager because I feel that the patients need that inner peace.'

Sub conclusion for person centred practice

While many of the basic spiritual needs (Koenig, 1994) that might be addressed within the normal, daily activity of healthcare were not articulated they were covertly expressed: - 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 and the need to find meaning and purpose in life. This was evident not just for patient care but also for staff support.

These internal issues presented much more of a challenge than the physical tasks required on a daily basis by a nursing team of highly skilled carers. Guidelines and policies have been written to address the soft issues of compassionate care, but the question remains of implementation. The internal trauma of changing circumstances, for which there is no book, is a continuing discussion not because it either needs addressing nor because there is no definition, but because the people resources required are significant and costly. Compassion, the bedrock of spiritual care, is demonstrated through seeing; touching and acting – all of which demand a pre-requisite of the physical presence of a listening human ear and a hand to hold.

3. Education

Although more than half of the interviewees had been exposed to previous educational training on spiritual care none of this had taken place in the last five years. More managers than either staff nurses or health care workers had received training but there did not appear to be a dissemination of this training to those who were involved in personal care of the patients. Some of this was due to lack of time, or the perception of the managers that they could not provide the training at the level at which they had received it. Many of the interviewees, mostly managers, asked what education and training was available and some displayed insight as to why they needed it or even what kind of education they would benefit from either as a group or individually.

The literature review highlighted a lack of educational resources. However, this study found evidence of many resources but a lack of availability of time, promotion, accessibility and management responsibility in recognising the need for it.

It appeared that rarely were updates delivered on spiritual care, and although training did exist most learning was based on previous opportunistic experience:

H18 A nurse was..... a palliative care nurse and taught a lot of spiritual care. I have never forgotten some of the things she said, and she taught as she was working with us. It was great. No one has taught me anything (formally) but I picked things up for myself.

The interviewees volunteered information regarding spiritual care input in induction or SVQ training and some were not sure if the basic training offered had any spiritual care component:

H25 ....although the SVQ had contained some information about spiritual care it had no depth and really did not lead to a good understanding of either different religions or what is included in spiritual care.

N13 ..... think that the induction process for new staff includes a spiritual care element. It is provided by the NHS and is part of service innovation with a focus on the first year of service.

On asking what spiritual care resources were available either for education for the staff or for spiritual care of the patients there was an acknowledgement that there must be resources, but many were unaware of them.

N8 In my previous job I had a resource folder for ethnic minorities which had information for death and dying. Also, information on diet. It would be good to have this here. My original nurse training did have a spiritual component. I also did a course.....7 years ago and from this developed a resident quiet room (in my last job) which was really helpful to the residents.

When there was training available it was well received and implemented appropriately with good evaluation:

N10 I have been to a FIOP (Faith in Older People) 'Fresh air for the elderly' and it was brilliant – in fact we have just recently added this to the care plan here. Also, I went to a really good seminar with the chaplaincy 5 years ago – the minister had really got it and was very good at explaining just what spiritual care meant in our setting. It was 2 hours every week for 6 weeks.

Some nurses said that they would like training, but no one had told them of anything and they did not know how to go about finding out. Part of this was an issue with time, because there was no time to deal with their CPD on shift and when off duty they were too tired. Some of them said that all their CPD had to be conducted in their own time so they could only access information that was on the internet rather than the intranet. Many staff said that they wanted to learn how to 'make connections' with the patients as they felt that was an

important concept. They also recognised the need to take education seriously – in order to ensure they were offering the best service to patients, but this often meant undertaking professional development at home.

N2 Well at present we have to do all our learning at home – so we do learn pro at home as there is not enough time while we are on duty. Also, if someone is on the computer doing their learn pro then no one else can go and use the computer. But if we did have learning then it would raise the awareness of spiritual needs. We give out tea/biscuits/meals but never spiritual care – it always has the last priority, the lowest priority.

Many of the staff offered ideas as to a learning wish list and also the preferred methods of learning.

N12 More insight into the definition of spiritual care. Perhaps a workshop or a group would help but do it as part of competency – or even mandatory. It should be basic training rather than an update as I need to gain more knowledge

S14 How to speak to the patients especially about their faith – how to approach them. How to talk to patients with difficulty in communication

N8 A resource folder would be good. As this unit is a palliative/end of life care we need chaplaincy involvement to discuss these particular needs with patients and relatives.

and learn from them.

In fact, some of these learning desires represented a real sense of passion for learning for the sake of the patients and the recognition that the whole person care could be significantly enhanced.

N12 I think there is an importance of spirituality in the human being – the mind, the body, the spirit, to make the person complete and valued. So, we need to see how we can fulfill what matters.'

There were times during the interviews when it appeared that it was not so much about wanting to learn for purposes of CPD but for a personal understanding as to the meaning of life.

H19 A training that would tell me what it all means.

H16 I would like to know more and understand spiritual care. I hadn't thought of spiritual care as anything other than religion before now but having thought about it I do all of those things on that list (Koenig's review) I just find it hard to put into words.

N5 I would always do my best, but I don't know what spiritual care looks like, so I don't know what I need but know I need something.

During the course of the interviews it was recognised that the staff themselves received little support in terms of education and the challenges of end of life care. They developed their own sense of resilience, often together in teams, but also individually as they coped with very demanding and difficult circumstances. Two educational themes emerged – the recognition of the need for education and spiritual support for the staff – however that was defined. They talked about the need for group work to support and affirm each other. Participatory and interdisciplinary learning featured highly during the conversations. There was a real sense of belonging as they spoke of each other as 'family' and what an 'amazing job' they were all doing – particularly from the nurse managers.

N10 If I see the staff doing something really good I send them an email because I believe it affirms them as they need spiritual care just as much as the patients.

Some of the nurse managers felt that it was themselves that should receive the education and then disseminate it as appropriate because they felt spiritual care required direction and leadership. Many recognised the fact that staff needed reflective time (now endorsed by the Nursing and Midwifery Council) and that the essence and outcomes of this reflection would impact on patient care.

N9 'I don't think we deal with it well enough. I need more support personally as a manager, so that I can then in turn offer support. I am absorbing staff issues as well as patient worries so need support myself.

H16 .... there is a lot of dementia at the present time which makes us stressed because we don't have enough staff. I cope with it by going to the staff room occasionally and count to 10.

The most difficult conversations focused around the subject of death and dying. Staff wanted more education in how to affect a 'good conversation' that enabled them to deal with these later stages of living.

H15 It would give a better understanding, a bit more about why the patients are feeling the way they are. The different stages of worry before dying – we need to know that. Why they don't want to see their visitors sometimes – that is really hard. What can we say to the visitors then? Also, it would be good to deal with the difficult conversations – about death and dying.

N3 Staff get their support during supervision particularly in relation to deaths in the home. We developed our own leaflet for spiritual care resources and phone numbers, contacts for our unit. It's really about getting some input even if someone dropped us an email or phoned up to see if a patient needed a visit it would be something. Does anyone ever ask about these things or how their life journey is going to be affected or impact their lives? This is their final port of call, but no one speaks about it. It is the elephant in the room subject and no one ever asks the family what they think about it either. We need to talk to people about death and not miss it out; we need to be open about it.

Confidentiality was raised as one reason for not raising the profile of spiritual care because by doing so there might be a restriction of patient information amongst the staff team.

N6 Sometimes a patient has told us something in confidence, so we would not discuss that (in the care team). There might be something going on in the ward, so we have to support each other. We must respect the staff if there is overload.

N5 As long as it is not confidential that the patient did not want handed on then it will be written in the nursing notes and also on the handover sheet. If it was detail that should not be shared, such as a disclosure of some sort, then it should be phrased appropriately – and not be made public on the records that can be accessed by anyone.

Protected learning time was evident in some of the units and the staff were very positive about the need for training, particularly with regard to person centred practice.

N10 Staff meetings – I constantly bring up person centred care.

N1 Need to see yourself before you see others. I have always given space for spiritual care input.

When asked how education would enhance their present practice the replies were wide ranging:

N3 ... would increase confidence in supporting patients and relatives. It would perhaps help to pick up 'clues'; be more proactive and ensure 'comfort' to the patient.

N5 We work with old people so death and dying for instance – if someone asked where would they go when they die I wouldn't know how to reply so with training I might know how to address this. Also, I want help with how to be comfortable in the silence.

The staff also wanted to know what resources were available to them in the community but did not have the time to go looking.

N7 Volunteer services – what can be used appropriately. Also, further development of the advocacy role as needed. So, it would be good to have more learning on this subject.

Never once did we hear complaints about either the NHS or the extreme circumstances in which some of the teams were working. Rather we heard plausible explanations for the lack of resources and the fact that the staff recognised the need for NHS economy. Some nurses even recognised that implementing spiritual care would have minimal financial implications nor add much to the daily routine.

N8 There are resources on the intranet which we use. In one situation we used this for a Muslim patient who was dying but there wasn't enough information on the intranet and, so we went to the internet and found what we wanted there. The intranet did not go into enough detail as to the respect and dignity that was to be accorded to the patient in this situation.

There appeared to be an assumption that it was possible to identify all the needs and resources required by a patient to fulfill their patient centred care on their immediate admission. As the initial admission forms only ask what religion a person is, it does not appear to have the capacity to have an understanding as to the spiritual care required by the patient. There also appears to be a lack of communication between hospital bases on occasion which means the narrative has to start all over again with a new admission. A person's story should follow them from place to place, creating new information as they travel – just as in life's journey we also create new stories but carry them with us because we are able as healthy individuals to articulate them.

While we frequently heard that there were not enough resources, we discovered evidence of resources available which were either unknown or not available for use in that particular unit. Where there were no resources the staff themselves became innovative in various ways organising tea dances; dominoes; pie and pint nights; quiz nights; Christmas parties. They were sometimes able to involve the relatives as a 'resource' when there were no volunteers on the units. In fact, some relatives went on to become volunteers after the patient had died creating for themselves a way of coming to terms with their bereavement.

A frequent conversation involved the prioritising of the budget by the ward manager which necessitated in them choosing either another nurse or HCA or SAC. It seemed that not often did the manager choose a SAC but rather required someone who could undertake clinical tasks. It was felt that the SAC should be the one with the ability and time to undertake many of the spiritual care tasks, but it was also recognised that without a SAC everyone else would undertake this level of care.

Prioritising the budget was a frequent issue which often resulted in the manager needing to prioritise appointing someone to undertaken clinical tasks rather than a SAC. There were mixed views as to whether the SAC should take responsibility for ensuring spiritual care was undertaken, given their time could be more flexible, or whether it should be everyone's responsibility.

N12 We are prepared to lose part of the nursing assistant budget in order to employ a social activities coordinator because this is a priority.

N8 We don't have an activities coordinator ; there is one downstairs for the psychiatric wards. To have one would mean sacrificing nurse hours and there are not enough nurse hours as it is. Patients sometimes join in downstairs if they are fit enough to go on their own as we do not have enough spare staff to go with them.

N6 There had been a hope that an activities coordinator would be appointed but the decision was made not to go ahead because the capacity of the patients did not meet the criteria and it was felt that such a post would have limited value.

N10 I took a budget from a Band 2 and moved her over to social activities coordinator because I believe so much that we should have this additional care of the spirit in the ward setting.

Sub conclusion for spiritual care education

The literature review identified guidelines that recommended spiritual care education for all healthcare staff. There was also evidence of educational resources across the country. However, there was a dearth in the availability of time to access these resources and inertia on the part of senior management to either recognise the need or to implement what already existed. While training is the key to the success of implementation there was no evidence in these units of following an implementation strategy nor of spiritual care learning standards for all staff.

Two main sub-themes for education emerged during the study - the first was that of spiritual care resources available for patients in some of the units where it was deemed appropriate, although this decision did not always seem to be made by the managers of the units who knew their patients. These resources are given at the end of the community involvement chapter. The second was that there were educational resources available for all members of the staff teams in the HBCCC units many of which they had no knowledge of or access to and these are identified here:

NHS Lothian spiritual care training programme, developed in response to requests for training from various disciplines and units:

a) Medicine of the Elderly – 'Spirituality at the End of Life'

b) Continuing Professional Practice Development – The Final Act of Care – 'Spiritual and Religious Care – Multi-Cultural and Religious Diversity Issues'

c) Foundation In Critical Care – 'Spirituality in the ICU Setting'

d) Palliative Care – ‘Spirituality in Palliative Care’

e) Weekly staff induction – face to face introduction to the Spiritual care team for all new NHS staff

f) Paediatric nursing staff – mandatory updates: Spiritual Care in situations of loss and bereavement

g) Paediatric health care support workers – mandatory update: Spiritual Care in situations of loss and bereavement

h) The Spiritual care team act as professional supervisors for a range of student placements: medical students; nursing students.

The Spiritual care team facilitates group staff support and debrief sessions at the invitation of medical and nursing staff. This is usually in particularly complex or traumatic cases. The team also offers one to one support for staff e.g. after complex and challenging cases, following personal bereavement or the death of a close colleague.

There are also many other courses on spiritual care issues:
Higher Educational Institutions training in spiritual care:

Napier University http://www.napier.ac.uk/key-facts/schools/shsc-key-facts New undergraduate programme in spirituality; MSc programme for Palliative Care

Queen Margaret University: http://www.qmu.ac.uk the present undergraduate course on psychology examines the psychology of spirituality and religion.

McMillan Nursing http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals two year spiritual care training

NES (National Health Education for Scotland) which is a vocational educational pathway within spiritual care and plans for future curricula within NMAP: http://www.nes.scot.nhs.uk/resources/LocalDeliveryPlanfiles/assets/neslocaldeliveryplan2016-17.pdf

- Sage and Thyme http://www.sageandthymetraining.org.uk relating to values based practice
- NES Person Centred Practice http://www.effectivepractitioner.nes.scot.nhs.uk/learning-and-development/clinical-practice/enhancing-person-centred-care.aspx
- CRUSE bereavement training http://www.crusescotland.org.uk
- Faith in Older People (FIOP) Spiritual care training presently being piloted in independent care homes; Fresh Air and Death and Dying http://faithinolderpeople.org.uk/Home/spirituality.php

The following are resources specifically related to staff working within the NHS:

- **Support Around Death Scotland | Support Around Death**
- *www.sad.scot.nhs.uk/*
- This *NHS Education* for *Scotland* website aims to *support* health and social care staff who ... and are looking for information on end of life or *bereavement* care.

- **Education and Learning Resource | Support Around Death**
- *www.sad.scot.nhs.uk/education-learning-resources/*
- Death Certification: Identifying Common Mistakes module. *Learning* · Spiritual care matters: an introductory resource for all *NHSScotland* staff ... This online forum enables those who work with the *bereaved* in *Scotland* to network and share ...

- **video wall | Support Around Death**
- *www.sad.scot.nhs.uk/video-wall/*
- This page acts as a repository for the *NHS Education* for *Scotland* animated films ... website and these videos deal with issues related to death and *bereavement* ...

- **e-learning modules: Loss and Grief | Support Around Death**
- *www.sad.scot.nhs.uk/education-learning-resources/resource/?id=1119*

25 May 2016 - These 9 modules, produced by Cruse *Bereavement* Care *Scotland* in conjunction with *NHS Scotland* are available on Learnpro.

It was clear that the staff felt quite strongly about the manner in which they should learn. Some of the staff reiterated that they would like to have spiritual care group work as they felt that not only would they learn from each other, but they would also be able to support and affirm each other, especially as they discussed case based narrative. They wanted various skills in communication and time management. But they were also curious as to the work of what they called chaplains but is presently known as the spiritual care team – of which they knew very little. There was an understanding that touch is very important to patients who receive very little touch therapy other than clinical handling, therefore legitimate ways to hold a patient when offering comfort would be a helpful. Staff regularly asked for observational learning – how to recognise the needs of patients when communication was challenging.

Overall, there appeared to be an inequity of resources, delivery of resources, access and knowledge of them. While some units did have exceptional resources, others had none and no way of delivering them. This was not a post code lottery as it was all within one health board, but rather a unit lottery. This personal iterative process was continuous as relationships in the units developed. However, there is recognition that nurses lack clarity when assessing patients for spiritual care (Wynne 2013). In part because they have gaps in their knowledge as to the definition of spirituality but also because there is uncertainty about how to assess and who does the assessing. Baldacchino (2015 cites Ross et al 2014) whose research showed that nurses consider themselves incompetent to deliver spiritual care.

Baldacchino (2015) made educational observations during her research and recommended the following:

- Education of health care staff is motivated by assessment of competence
- Clinical practice implements theoretical learning
- Management fosters spirituality in the workplace
- A personal understanding of spirituality enables and empowers implementation of learning.

These recommendations reflect the findings of the authors study and their consequent recommendations.

4. Community Involvement

18 of the 29 interviewees said that they had community involvement in their units while the rest said that they had no community engagement at all.

In some areas there was a very effective staff support system which made up for the lack of community involvement and seemed to underpin the spiritual care that they were trying to offer, despite the lack of resources. However, this did not in any way diminish the need for community connection. Almost all the areas had a good internal staff team support system, and in some cases these particular teams had worked together for years forming a family of care. Some of the newer teams worked in huddles where they had weekly multidisciplinary meetings to discuss each patient. One said that issues of the spirit could be discussed at this time. Although the teams did not articulate reflective practice it appeared that these huddles were of a reflective nature.

The authors found it difficult to differentiate between community involvement with the patients and the support and encouragement that the staff received through engaging with

the community. It seemed that the various groups held each other up and gained mutual benefit as a result.

In each unit there was a recognition that team work acted as the basis for staff support and safe evidence based patient care and that the team consisted of more than the healthcare staff. 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:

N6 A chaplain visited every week until she went on sick leave. Currently a retired catholic nun (Sister Angela) comes in regularly to chat.... Some ministers do come in but there have been instances of ministers declining because it is 'too upsetting'. Sometimes they are not available.....The minister said 'no' when asked to come in, because he found the lead up to death too upsetting.....That can be devastating to need a chaplain and not have one available.'

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, they were seen as people who cared enough to give up time to support both patients and staff.

H23 Patients are now more ill and needing palliative care. Previously they were more independent. That's why it's so good to have befrienders to sit and talk to them because they have more time. There is less interaction because of dementia – patients get agitated and not always able to engage. It is good to have a volunteer who has time to talk and be with someone. Arts and crafts were good as it gave patient's something to do.

The SAC in one unit who was about to commence this new role was excited about plans to involve the community because this appeared to give the patients identity:

N12 Well as I have just got this new role I have many plans. One of the patients is wanting to involve the community in a mobile friendly garden for instance. So, we have started on growing a smelling garden and I hope to make this into something much bigger – a place for the patients to be themselves in.

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 themselves:

S14 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.

H22 Music groups downstairs invite us but most of our patients are not able to go by themselves.

H20 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.

N9 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.

However, there were activities in some of the units that gave very positive feedback:

H23 The League of Friends and also visits from volunteer, and the arts and crafts person. They bake cakes and make cards.

H16 Music in Hospitals come in once a month. The Red Cross also do a befriending scheme and they come in twice a week to take a patient to the local café for a coffee. There is also something with the High School where they befriend one of the patients – these are young people from the 6th Year on a Friday after lunch.

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

N10 Occupational therapist runs a breakfast group and a newspaper read – this is from the Health Board. I try to have someone come in every day and I pay them because the patients pay into a fund.... We also have an art therapist and art teacher with 2 groups of 4 people... I also pay befrienders as there are quite a few with no relatives. We have a music therapist as well.

Enabling and empowering patients in HBCCC is a skill which does not belong to clinical staff alone. It seems that while the tasks of ensuring a patient's wellbeing are important, lifting the spirit above the physical brings about a change in the emotional temperature of the patient.

H24 Monthly music in hospitals who come here for concerts and singing is really good as singing along is good to see because you don't often get interaction with the patients. Outings lift their spirits – we see changes, especially when they see places that they know, and they start to talk in ways that they don't when they are in the ward. Holidays also make a huge difference – it is quite amazing when they come back to see those changes. They talk, they smile.

The enriching of people's lives often happens by chance, but when someone is in hospital and relies on those around to promote that enriching then the narrative of a previous life is essential in which relatives and friends can play a significant role, sharing the rich information needed to make the story continue. The 'Getting to Know you' forms are the most commonly used but do not always get to the heart of what matters to an individual., Given that time is critical in exercise there is perhaps an opportunity to involve relative, friends and recognized volunteers.

Hand holding in particular was mentioned several times as a way of enabling patients to feel loved, wanted and still a part of community, reminding them that others were around them without gloves as a clinical barrier. Touch conveys a thesaurus of unspoken narrative, but society has little time to devote to such a basic and often restricted act of kindness. Barriers of infection control and lack of compassion often stop this small act.

H22 Whatever means the most to them; ask them, get to know them; Hand hold; massage; hair combing; tactile movements; they get little physical contact which is sad because it is nice to have your hand held.

It was clear that community activities of spiritual daily living were based on the documented narrative from the patient:

H23 Respond to the small details of what the patient needs –make sure to report on things between shifts –moods; settled etc. so that there is sharing at each report session. Report on anything you do.

N4 (Documents are) used in planning activities, to create opportunities and to develop engagement. These help us to plan those activities that they (the patient) are interested in – so we work around the information given to us.

When asked who should provide spiritual care, there appeared to be a lack of understanding when it came to whether the community should be involved or even what that involvement looked like:

N12 The staff have to do this - play dominoes or do a quiz. There is no regular links with chaplaincy –this is not a priority but something that would come from the nursing staff if they

initiated it. I would like it to be a priority. 'Myself as manager because I feel that the patients need that inner peace.'

4c N1 I appreciate we don't have a chapel or a quiet room, but we should take this on and organise it. But we don't because we have no time and not enough staff. Neither do we have any dedicated funds that we can use to, for instance, take patients out for Palm Sunday or bring in a minister, singer or anyone. It's more looked at that nurses are nurses – tasking rather than looking at the social aspect – or spiritual aspect. We need to put this altogether rather than separate it out.

There was however, a sense that the spiritual care team could play a significant part in the spiritual care of the units particularly with regard to end of life:

N12 the chaplains were very proactive – I saw how much they did for a particular man who was preparing for dying, so the first thing I did when I came here was to think about how to prepare patients for end of life and departing in belief. So perhaps that is why I am quite proactive in asking for chaplaincy help in this unit particularly when there are end of life conversations and you want them not to be afraid of dying, this monster, but to be at peace. People should never die on their own – if their family are not in I will make sure someone is holding their hand.

Relatives have a need to see their loved ones cared for and still functioning as part of society. Not only are they part of the narrative and decision process but also can be a part of the unit family of care, unless for whatever reason their own needs conflict with that of the patient needs. One HCA (H25) highlighted how sad and isolating it was for patients who had no family or friends to visit and this put a reliance on staff who felt constrained by the time they had available. If relatives are not present, then there is an unfulfilled gap in spiritual care:

N4 Relatives also like to see the person as being functional.

N13 Sometimes there is a tension between what the patient wants and what the relatives think they should have – important to work with relatives to focus on what the patient wants at this stage in their lives even though it might be contrary to what they have asked for before.

Sub conclusion for community involvement

The provision or not of community involvement highlighted the vast differences to be seen within one very small geographical area. The list below gives an overview of all the

resources that are available to the HBCCC units in this area and the take up of those resources in the units. It was evident that all five groups of peoples, spiritual care team, 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. Spiritual enrichment is enabled through patient narrative and the stronger that link the more enriched the unit experience, not just by the individual but by the whole unit family. Implementation of the individual patient narrative however, presented challenges that often seemed insurmountable and frustrating in the extreme.

Resources which were available:

- Talking mats – most did not know these existed. We approached the talking mats group in Stirling and they admitted that there was no spiritual care component (apart from a church picture) but would like to work with us to address this. None of the units used these as a resource.
- Advice for last rites in various faiths seemed to be lacking, although there is a resource book for this in Lothian, many did not know it existed. Only one unit actually had this to hand.
- Intranet help – this is in a very basic form and did not appear to be detailed enough to deal with the challenges and issues of various faiths. Only one unit had used the intranet and then went on to use the internet as they did not find enough information on the intranet.
- Resource Folder: There was a resource folder in one area that the nurse knew of, but felt it was too black and white and that the softer issues of spiritual care was

missing, although this could not be articulated. One unit, unable to find anything for spiritual care resources, developed their own leaflet with contacts in and around the unit.

- Music in Hospitals – this was only available in one unit but appeared to be available in other wards surrounding the HBCCC units.
- End of life care plan which included spiritual care - One unit had an end of life care plan that they had developed which included spiritual care.
- Chaplaincy or spiritual care teams -There was evidence of notices pinned up in one unit – if you need a chaplain get in touch, but the interviewees at this unit did not mention they had seen this.
- Mobile friendly, smelling gardens that were risk managed. This was in the planning stage in one of the units, seven of the other units had some form of outdoor area, but one unit was unable to use any outdoor area due to different agencies using the same building.
- Rotation of Churches together, taking services in different homes. Only one unit had organised spiritual services taking place on a regular basis from external faiths.
- Therapets - used by one unit
- Massage: head; hand and Indian - used by two units
- Community Volunteers/befrienders - some were free and some required payment, both at the behest of the unit manager, requiring administrative organisation. Three of the units used these.

Discussion of findings

The SEHD (2002) recommended that one session of chaplaincy is dedicated to 25-50 long stay beds and that all staff clinical and non-clinical are educated in such a way as to be able to assess the need in each patient for spiritual care. The spiritual care team is going a long way to addressing some of these issues, but its own resources are thin. It appears that there are other agencies from both within and without the NHS who could offer such education and resources that are required to redress the balance of learning and implementation in these units. There is no doubt that the similarities between the extracted data from this appreciative inquiry and previous literature are startlingly obvious. However, what is not clear is why the statements that have been previously made are not being implemented in practice. There have been small efforts made to make changes in some areas of Scotland with various guidelines being introduced from some Health Boards, but there does not seem to have been a consistent approach across the country which has resulted in sustainable changes.

In every single unit the interviewers found compassion; expressions of value for human kindness; understanding and respect and above all a sense of family who supported one another in the extremes of life. All of these represented the definition of spiritual care expressed at the beginning of this paper. However, while there appeared to be little recognised or standardised methodology in the way that this was delivered much of the care was initiated through instinctual understanding of the needs of another human being.

If spiritual care is understood then the time factor, a significant element in this study, assumes lesser proportions as the skills of 'bathroom sink' conversations are employed on a regular basis. Instead of becoming another task spiritual care is integrated into the warp and weft of normal living.

Lack of standardisation in education produces a sense of frustration on the part of staff who recognise that there is more to caring than tasking and therefore the daily battle with stress

and reduced resources produces a cycle of diminishment. While resources appear to be available in abundance there needs to be a greater awareness of the ability to use those resources. In addition to this the skill of time management and the process of change can generally only be learnt through formal education in order to facilitate quality improvements in practice.

The educational resources have been previously developed according to the requirements of guidelines, yet it was evident from the interviews that these prolific courses are not made available for staff who are at the point of delivering the very care the courses are designed for.

There is a notable lack of community involvement - where the opportunities were limited and random in application i.e. one unit had significant involvement another had none. The staff almost always talked about their lack of time yet more emphasis needs to be placed on the mutual benefit of community involvement to staff and patients. Embracing this may address some of the challenges of time given that the staff could then focus more on the tasks that are required to be completed in such complex patient care.

This study has highlighted the differentials between various long stay units that exist in one health board alone and therefore begs the question as to whether replication of its findings would exist in another health board with a demographically different population, such as a rural health board, where the population is smaller and hypothetically able to offer different resources.

Koenig's table results:

The results from the modified Koenig questions showed staff perception of care from admission to dying. Despite the units being predominantly for end of life care the lowest collated rating was preparing for death and dying. However, person centred practice, personal dignity and a sense of worthiness was at the top of most participants' agendas.

Meaning, purpose and hope came second although several commented that they were all important depending on the different stages of life when the various concepts took on another priority.

Conclusions

Reciprocity of understanding spiritual care has benefits for both staff and patients. Each draws resilience from the other increasing the depth of every single contact or engagement. The resources for education are all in place – what is missing is the ability to access training both in terms of time, resources and empowerment from management to enable their staff to professionally develop their roles.

The conclusion of this study is to recommend a rounded educational package that is accessible for all HBCCC required as a mandatory part of initial training and ongoing CPD. This would be drawn from existing resources so that a degree of choice could be exercised ensuring personal development and desired team skills. The areas of choice are found in Box 1 as a summary of previous recommendations, ensuring that the four pillars from this study are included, namely time management; person centred practice; spiritual care education and engagement with the community.

For successful implementation of this recommendation it requires support and encouragement from all levels of management including stakeholders who hold the key to mandatory guidelines.

Defining the gap between existing resources and implementation of spiritual care guidelines would require further research. A greater awareness between government and healthcare workers may facilitate an increased uptake of spiritual education in these vulnerable areas of the NHS. Whatever the case this study shows that there is a gap which requires bridging in

order to increase the capacity of staff development in spiritual care and so allow a very vulnerable group of patients the right to live and die in the manner of their choice.

Summary of previous a priori recommendations aligned to the findings of this study:

1.	Barbour (2013) Byrne (2008) Higgins (2013) Mowat and O'Neill (2013) Pulchalski et al (2014) Wynne (2013) This study (2016)	• Listen to the narrative/being alert to hear patient meaning of life • Use formal spiritual assessment tools • Understand and be educated in the individual religious/cultural needs • Use additional resources such as sensory gardens; quiet rooms/presence/reflection • Use techniques such as mindfulness • Acknowledge special needs • Value input from specialist knowledge such as chaplaincy teams/Community Chaplaincy Listening Found various aspects of the above but no consistency across all HBCCC units
2.	Byrne (2008) This study (2016)	• Use affirmation techniques to affirm identity • Be flexible Found some evidence of these technique in most of the HBCCC units
3.	Dopson (2005) Mowat and O'Neill (2013) This study (2016)	• Use resources which trigger memories such as music/song/worship/prayer/ritual Found most HBCCC with some but not all the above

4.	Higgins (2013) Howard (2012) Mowat and O'Neill (2013) Walters and fisher (2010) This study (2016)	• Connecting with religious ceremonies or church to maintain personhood • Linking with church community and/or faith bases • Provision of faith resources e.g. Bibles; texts • Give space to staff to reflect on faith/ spirituality • Aid individuals to find their own sense of peace Found little evidence of the above in any of the HBCCC units
5.	Kevern et al (2013) Levison (2005) Mowat and O'Neill (2013) Pulchalski et al (2014) This study (2016)	• Appropriate training in spirituality • Ensure that care plans reflect the spiritual nature of the patient and review regularly • Review data gathering tools with staff and Health boards • Ensure patient needs are met • Care for all faith or no faith • Practice compassion Found some evidence of the above in the HBCCC units except for training in spirituality, most of which was historical.
6.	McSherry (2010) This study (2016)	• Ensure that spirituality is not segregated as a separate issue but is part of person centred practice. Found that the perception of most staff was that spiritual care would become a subject on its own and therefore an additional task to be learnt.
7.	Paley (2008) This study (2016)	• Develop chaplaincy teams to include all/no religions Found that the chaplaincy team was all inclusive regardless of faith or no faith.

8.	Vivat (2013) Walters and Fisher (2010) This study (2016)	• Consistent approach to implementation of policies in UK • Understanding of management challenges for training staff • Clarity on identification of patient needs and solutions for implementation of those needs Found no consistency in line with previous recommendations or guidelines.
9.	Walters and Fisher (2010) This study (2016)	• Define the line of responsibility for spiritual care • Offer regular/mandatory training in spiritual care Found that there was no defining line of responsibility for spiritual care and training was irregular mostly nonexistent.

Recommendations

This study recommends a two pronged approach to the educational needs of staff caring for patients in HBCCC units :

First :

1. The establishment of a Short Life Working Group of key educationalists to develop a structured approach in using the resources available for professional development of spiritual care in HBCCC units.

2. The implementation of a single resource that would bring together all the teaching elements into one place using an appropriate channel for spiritual care education.

Secondly,

1. Disseminate the results of this study to all HBCCC units in Scotland.

2. To develop an implementation plan for spiritual care educational resources with a subsequent impact study to ensure succession in professional development.

Acknowledgments

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Appendix i.

Questionnaire

Questionnaire for Spiritual Care Education in Continuing Care units in the NHS: A collaborative study with Faith in Older People and NHS Lothian Healthcare Chaplaincy

Aim of the study and questionnaire:

> A twofold scoping exercise examining existing (a priori) literature on spiritual care in continuing care units and secondly staff in small NHS continuing care units as to their perception of the spiritual needs of residents and how these spiritual needs can be effectively achieved through education and support of NHS staff.

Background

This exercise is based on anecdotal evidence from NHS staff in continuing care units that they have identified learning needs in the support required to offer spiritual care to their residents. A previous small study (Welsh, 2015[1]) in April 2015 looked at care home staff members understanding of the concept of spiritual care and concluded that more work was required to support their education. There was also a recognition that the roles of allied

[1] Welsh, H. 2015 Addressing the Spiritual Needs of Older People in Care Homes Published by Faith in Older People

professionals such as chaplains and the wider community could be encouraged to take part in providing for the spiritual needs of residents within this setting.

The study involves a survey of staff views about spiritual care in nine continuing care units in NHS Lothian. A questionnaire, which has been piloted and further developed, will be used. As this study only involves NHS continuing care unit staff, and not patients or residents, NHS ethical approval will not be required and only those staff who have given written informed consent will be included. The continuing care unit staff we are suggesting would be appropriate for inclusion in the study are Activities coordinator; Nurse Manager and Health/social care worker.

Continuing care unit managers will be asked to give written informed consent to carry out the survey in their unit. At any point the managers or staff can withdraw from the study. The study is projected to finish on 31st October 2016 with the results being published as soon after this date as is possible.

The published study will ensure that anonymity and confidentiality of all information given in the process of the questionnaire will be kept.

Information and consent form for participant

Having read and understood the background to this study I agree to take part in the questionnaire which will be undertaken by authors: ☐

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Registered Charity SC038225 Registered Company SC322915

I understand that at any point I can withdraw from the study or refuse to answer questions. I understand that the interview will be notated at the time and then transcribed at a later date ensuring anonymity of all persons and place.

I will ensure that I adhere to the NHS Lothian policy of confidentiality with regard to residents in the continuing care unit where I work, and with regard to knowledge of all other residents in NHS Lothian where I may have previously worked.

Name…….

Signature……..

Designation……..

Workplace……..

Date…….

Signature of researcher……

Date…….

Copy given to interviewee for own records ☐

To the Manager of the continuing care unit:

I have read and understood all the information provided by the authors as background to this study. ☐

I give my permission for this study to be conducted in this continuing care unit, understanding that I can withdraw my staff at any point.

I understand that my residents and staff will be anonymised in any published work and that the place of residence will be unidentifiable.

Name…….

Signature……..

Designation……..

Date……

Signature of researcher……

Date……

Questionnaire for Spiritual Care Education in Continuing Care units in the NHS

Part I

What you do to learn about the resident during the initial admission assessment

1. What does the term 'spiritual care needs' mean to you?

2. Who conducts the initial assessment with the resident?

Activities Coordinator ☐

Nurse Manager ☐

Health/social care worker ☐

3. What questions are asked that relate to spiritual care?

4. Other research [2]has identified some important steps of care and the following seven phrases written on the cards laid out in front of you have been modified from this research. Can you put them in the order that you feel best describes spiritual care for the residents of this continuing care unit? (1 being the top priority)

Personal Dignity and sense of worthiness	

[2] Koenig H (1994) Ageing and God: Spiritual pathways to mental health in midlife and later years, New York: Haworth Pastoral Press

Meaning, purpose and hope	
Rising above circumstances	
To love and serve others	
To forgive and be forgiven	
Engaging in religious behaviours	
Preparing for death and dying	

5. How do you assess what is important to the resident in terms of their spiritual wellbeing?

Part II

The response to identification of residents' spiritual care needs.

6. How do you act on those needs that result from the resident's story?

7. Having identified what is important to the resident's spiritual identity how do you confirm this with the resident?

8. What steps do you take to communicate this information to the rest of the continuing care unit team?

9. How do you enable the resident's spiritual care needs to be fulfilled as part of their daily life in the continuing care unit?

Part III

Identification of educational support required by the care staff in order to assess residents' spiritual needs and deliver the care on a daily basis.

10. Has any of your previous training, learning or work-related experience included a spiritual care component?

    Yes ☐ No ☐

11. If you answered yes to the previous question, please describe.

12. In your present role can you identify and describe any spiritual care learning needs?

13. If these were met, how would they enhance your practice in your present role?

Part IV

Community Involvement

14. Do you have any community involvement which enhances spiritual care in your continuing care establishment?

    Yes ☐ No ☐

15. If the answer is yes, please describe this involvement from the community or any previous involvement that existed and its reasons for discontinuation.

16. Who do you think takes responsibility for spiritual care in this continuing care unit or who do you think could take on that responsibility?

    Do you have any other comments to make regarding the spiritual care of residents in your continuing care unit?

Thank you very much for helping us to complete this questionnaire. If you have any further enquiries on the study, please do not hesitate to contact:

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Appendix ii

Literature Search and review for the subject:

Caring for the spirit in continuing care units

	Reference	**Comment**
1	Barbour, C. (2013) Spirituality at end of life: where the HCA/AP can help *British Journal of Healthcare Assistants* 7(6) pp378-379	Case Study of spirituality in the NHS and findings: • Listen to the narrative as it is impossible to separate person from spirituality • Recognise the completeness that spirituality brings to the person – same as the physical body parts. **1.** The right questions should be asked in order to elicit the narrative. • Listen and listen again. • Use formal spiritual assessment tools • Highlighted the implications to care when adhering to faiths: food; dress; rites. • Recommendations: sensory garden; quiet room with aids to spirituality; mindfulness>holistic care; in depth assessments when residents are going to be spending the rest of their lives in one place; community involvement. • Acknowledge special needs and take all comments seriously. • Value the input from chaplaincy team

2	Byrne, M. (2008) Spirituality in palliative care: what language do we need? *International Journal of Palliative Nursing* 14(6) pp 274-280	• Spirituality – the essence of a person. • Needed to affirm the personhood and identity of each patient. • Flexibility is required to accommodate individual personalities and circumstances. • Patient narrative gives spontaneous connection to living. • Is spiritual support common to all to give or only to those who have had training? • Spiritual needs multi-faceted, multi layered. • Patient journey instrumental in challenging, changing practice. • Discusses need for education on world faith and cultures. • Understanding patient metaphor, symbol and narrative to express self, ensures whole person care.
3	Dopson, L. (2005) Soul Music *Nursing Older People* 17 (7) p39	Discussion on CD produced by Stirling University which recorded favourite hymns to encourage reminiscence and Sue Kirkbride's survey which examined the listeners of the CD. Conversations revealed a depth of spirituality according to the customs and traditions of their faith despite memory loss.

4	Higgins, P. (2013) Meeting the Religious needs of residents with dementia *Nursing Older People* 25(9) pp25-29	This article discusses the importance of life histories and assessments. It purports that reconnecting with religion might increase a sense of wellbeing, maintaining personhood. In respect to those with dementia, going to church or being part of a faith community was important as was prayer – 'a way of being' which gave hope. Recommendations: • Holding religious services in the care home • Keeping residents linked to their own faith base • Keep links with church community • Recognition of the importance of this to the staff • Attending local church/faith services with help from the community. • Private prayers • Provision of bibles or other spiritual literature • Allowing residents to actively take part in whichever way is possible. • Involving the staff with ideas – this also articulated the fear that surrounds proselytising which may cause offence to vulnerable adults. Discussed the need to be transparent about this fear.

5	Howard, H. (2012) Compassion in practice nursing. *Primary Health Care.* 22(4) pp21-23	This article examined Parish Nursing. Described as aiding individuals to find peace within a relationship with their God and to identify their own spiritual needs. Discussed compassionate blankets which gave opportunity for patient narrative. These were made by volunteers with various fabrics and colours, given to patients. Plan to develop this resource by using this scheme in nursing homes.
6	Kevern, P. Walsh, J. McSherry, W. (2013) The representation of service users' religious and spiritual concerns in care plans *Journal of Public Mental health* 12(3) pp153-164	Examines the 'poverty of vocabulary around spiritual issues'. Suggests lack of appropriate training in spirituality for mental health professionals. While carrying out the research the authors discovered that care plans have little relevant information on personal beliefs, suggesting care coordinators were either not sensitive to spiritual needs, had little insight or were reluctant to explore these issues. • Recommendations: Trusts review data gathering tools with staff. • Training implications require further development • Need to address patient concerns.

		• Regular review of care plans with articulation of meaning for the carers and service users.

7	Levison, C. (2005) Spiritual Care: Standards and Guidelines *Nursing Management* 12 (6) pp 18-21	• Examines the difference between spirituality and religion and gives clear definition of the chaplaincy collaborative. • Religious affiliation often omitted at patient assessment. • Lack of equity in service provision but clear imperative to care for all faith or no faith. • Spiritual care integral part of health care. • Training health care professionals in spiritual care embedded in NES. • Person centred care foundation.

8	McSherry, W. (2010) RCN Spirituality survey: A Report by the Royal College of Nursing on members views on spirituality and spiritual care in nursing practice *Royal College of Nursing Publication*	Largest survey that has been carried out across the country on spiritual care amongst nurses – represents 1% of RCN membership. Introduction discusses religious communities offering sanctuary providing earthly and spiritual needs, when the state took control the religious connections declined. Definition of spirituality (p15) was from Murray and Zentner (1989 p259). Purported that omitting the spiritual is not holistic but reductionist care. Results from the survey: • 43% considered spirituality and spiritual care as a fundamental aspect of nursing. • 92.6% indicated that all health care professionals are responsible for providing spiritual care in conjunction with patients' family and friends. • Nurses perceptions of spiritual care included: a need for meaning, purpose, a source of hope and strength, expressions of beliefs/values; spiritual practices; expressions of concept of God or deity.

		• 87-89.9% said that patient's themselves identified spiritual needs and the nurses were the passive listener or observer • 79.3% agreed that they do not receive sufficient education and training in matters concerning spirituality. Nurses feel inadequately prepared to deal with spiritual concerns. • Majority were in favour of formal integration of spirituality within programs of nursing education. At the end of the report the RCN recommended that spirituality should not be segregated to its own subject but rather be part of all holistic care. Segregation relegates a single subject to motivated parties only.

9	Moore, A. (2015) Spiritual solace without religion *Nursing Standard* 29(32) p23	This short article discusses the barriers that nurses have identified when introducing the concept of religion because the chaplains only represent a small cohort of religious entities. However, NHS guidance is making it easier to offer chaplaincy services to all patients rather than just those with a recognized faith.
10	Mowat, H. O'Neill, M. (2013) Spirituality and ageing: implications for the care and support of older people *Institute for Research and Innovation in Social Services*	Gives definition of spirituality and a range of activities which can support dimensions of spiritual care: • Spiritual Reminiscence • Spiritual history taking • Life review/life story • Music/Song • Worship/prayer/ritual • Presence/Reflection • Listening/Community Chaplaincy Listening

11	Paley, J. (2008) Spirituality and secularization: nursing and the sociology of religion *Journal of Clinical Nursing* 17(2) pp 175-186	Discusses the disparity between UK secularization and increasing attention academics are paying to spiritual values amongst patients. Cites other authors who have not substantiated their claims on the spiritual element of every person, claiming lack of definition of spiritual care. Describes the interest in spiritual care as 'nursification' (p181) – identification of issues which then become a health science. Calls for a need for hospital chaplaincy to extend its operations as 90% are presently Christian.

12	Pulchalski, C. Vitillo, R. Hull, S. Reller, N. (2014) Improving the Spiritual dimension of whole person care *Journal of Palliative Medicine* 17(6) pp642-656	Discusses the need for a shift from physical healing to whole person care. • Fundamental component of high quality compassionate health care. • Spirituality improves patient health outcomes; negative spirituality; decreases stress and burden of illness. • Spirituality involves wellness and health, therefore preventative health. • Addresses the complexity of solving spiritual needs as opposed to physical needs, which are often easier through tests and treatment. • Spirituality gives meaning and purpose to life. • Spirituality should be expressed through beliefs, values, traditions and practices. • Discussed the need to be alert to hear whatever gives meaning to the patient. • Recommend a model of spirituality which combines this with compassion. Education is a necessary part of this. • This article would want to operationalize spiritual care but also states that 'compassion should be the driving outcome for any health care system.'

13	Sadler, E. Biggs, S. Glaser, K. (2013) Spiritual perspectives of Black Caribbean and White British older adults: development of a spiritual typology in later life *Ageing and Society* 33(3) pp511-538	Proposes that spirituality is part of successful coping mechanism in life. Study examined two of the largest ethnic groups in inner London. Discovered a complex multi-faceted construct and often confused picture of religion. Interviewers identified the spiritual journey and personal definitions of faith: belief; death; after life and spiritual experience. Examined their coping mechanisms for changing life circumstances. Discussed four emerging spiritual categories found in later life: God to self; self to God; self to universe and self to life.

14	Vivat, B. (2013) Implementing spiritual care at the end of life: the UK *European Journal of Palliative Care* 20(1) pp32-33	Discusses the shift in providing religious care from religious professionals to health and social care providers. Gives statistics to show that religious beliefs have declined since 2001. Discusses the need for consistent approach to implementation of policies across the UK and the challenges for management when there are gaps in staff knowledge base. There is no clarity on the identification of patient needs nor how to address those needs once identified. Gave reference for Marie Curie Spiritual and religious care competencies 2003. NICE guidelines 2004 Scottish Spiritual Care Matters 2010 NES Vivat has also authored a book Oxford textbook of spirituality in Healthcare.

15	Wynne, L. Spiritual Care at the end of life (2013) *Nursing Standard* 28(2) pp41-45	This article proposes that spirituality is necessary in meeting end of life care and improves the ability to cope with ill health. Spiritual distress results in poor recovery and negative attitudes to living well. A spiritual assessment often means staff adhere to rites of dying rather than addressing the individual emotions, including those who have no faith. Discusses the intangibility and subjective nature of spirituality, with a need for individual, self-expressed spiritual care. Nurses also lack clarity when assessing residents or patients because they have gaps in their knowledge as to the definition of spirituality. There is uncertainty about how to assess and who does the assessing. There appears to be a lack of training to provide competent care. Concludes that effective spiritual assessment underpins best practice in end of life care. Discussed the use of spiritual screening tools: HOPE; HEGARTY'S 3 QUESTIONS.

16	Walters, G. Fisher, S. (2010) the development and audit of a spiritual care policy used across three hospices in England. *International Journal of Palliative Nursing* 16(7) pp 327-332	This policy addressed the training needs for implementation of spiritual care across the country and made the following recommendations: Spiritual care is the responsibility of all or at least many hospice staff. It should be in the hands of experts in the field ie chaplains. Hospices have adopted the acronym FIRM – Faith, identity, relationships, meaning. All staff offered half day of training in FIRM which was positively evaluated. Requires encouragement from managers to attend training, which should be regular and in working time. Management structure to accept the importance of spiritual care to ensure greater uptake of training. Greater spiritual input would be welcome from the community.

Appendix iii

Common themes from literature review

Individual Narrative	Importance of assessment which commences before admission and is a continuous live process, using constant review of spiritual temperature Spiritual history taking as an art/skill Intentional listening – listening with a purpose Tacit questioning – open ended with a listening content to elicit individual information Building resident identity through life history Allowing spontaneous connections Forming constructive patterns to challenge task orientated practice Use of tools and social activity to allow reminiscence and life stories Being constantly alert to all forms of communication from residents Being mindful of personal definition of faith or belief Ability to recognise spiritual needs through the narrative and identify ways of addressing those needs. Ability to interpret the narrative as spirituality rather than adhering to rites of living and dying. Interpreting resident language and communication

Person centred care (Holistic care)	Spirituality completes the triangle of body, soul and spirit, necessary for wholeness, shifting the burden of care from physical health to a comprehensive health care Mindfulness of the person by those around and by giving sensory aid to the memory. Flexibility from staff to allow the individual to flourish and to accommodate personal requirements and needs. Encourage the use of customs and traditions, linking to personal faith Being alert to spiritual enquiry/need to resolve past conflict, aiding residents to find peace and ability to cope with changing life patterns Active participation and individual choice, giving meaning and purpose to existence Chaplaincy services available for all people, faith and non-faith which may require renaming of the service

Educational Needs	Present lack of appropriate spiritual care training – this theme was present in almost all the literature reviewed. Lack of relevant information in care plans to inform care needs – therefore training required in assessments; narrative interpretation; use of spiritual care tools Staff in the NHS feel inadequately prepared to deal with spiritual personal issues – described as the final barrier to nursing care. Dichotomy of segregated spiritual care training or embedding into foundational learning at all levels Without training who delivers spiritual care and how is this delivery quality assessed? Some assert this should be entirely chaplain based, many others feel that it is part of the person centred care Education is required on two levels: knowledge based - cultures; traditions; world faiths and beliefs; tacit understanding – how people feel about their spirituality and whether they want to address needs they may or may not have. Address management understanding of the importance of spiritual care to enlist their support and encouragement for staff training. Use of spiritual assessment tools NES cited as one way of disseminating spiritual care education which would give a consistent approach to policy implementation across Scotland

Community Involvement	Community chaplains; listening services; relatives and interested parties were all cited as being important to the spiritual care of residents. The faith community has a responsibility for its parish. Small units are local neighbours and therefore should be embedded in the parish of community life. Chaplaincy teams are valued and integral to spiritual care Volunteers play a large part in offering spiritual care to residents and as such should be valued as part of the caring team with educational needs