

## ASSESSMENT AND DOCUMENTATION OF RELIGION AND SPIRITUALITY IN THE LIVERPOOL CARE PATHWAY FOR THE DYING PATIENT – HOW WELL IS IT DONE?

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*Abstract: Introduction: The Liverpool Care Pathway for the Dying (LCP) provides a standardised evidence-based approach to caring for patients and their relatives in the final days of life (MCPIL, 2009). Goal 6, Section 1 of the LCP assesses religion and spirituality. Methods: A retrospective audit of assessment and documentation of Goal 6, Section 1 of the LCP was carried out between 1.6.08 – 31.8.08. Following discussion with the MCPIL, a standard for 80% compliance was set. Results: Compliance with the 80% standard was not met. 50% of patients and 74% of relatives had their religious/spiritual needs assessed with them. 42% of patients had a religious tradition/spiritual need identified and 42% of patients were offered internal chaplaincy support. Internal discussion suggested Hospice staff were not always comfortable discussing religion/spirituality with patients and their families and that religion was easier to document than spirituality. Conclusions: Ways in which provision of religious/spiritual care to dying patients and their families might be facilitated were discussed internally and recommendations for providing this care were made.*

*Key Words: Religion, Spirituality, Liverpool Care Pathway for the Dying, LCP, Bereavement, Dying*

### Introduction

Over 55,000 people die in Scotland each year (Audit Scotland, 2008). Various tools to promote excellence in the terminal phase exist, several of which are mentioned in the NHS End of Life Care Plan (NHS National End of Life Care Programme, 2009) – one of these is the Liverpool Care Pathway for the Dying Patient (LCP) (MCPIL, 2009). The LCP is an Integrated Care Pathway for the Dying which was introduced in the late 1990s by Palliative teams in the Royal Liverpool and Broadgreen University Hospitals NHS Trust and the Liverpool Marie Curie Hospice. The LCP can be used by both Primary and Secondary care teams and provides a standardised evidence-based approach to caring for the dying patient and their relatives in the final days of life: it involves the use of shared multidisciplinary written notes (MCPIL, 2009). Goals are documented as ‘achieved’ or ‘variance’ within 3 sections (Initial Assessment, Ongoing Assessment, Verification of Death). Variances will inevitably occur e.g. if a patient experiences pain, there will be a variance in the goal “Patient is pain free” (Section 2, Ongoing

Assessment). The reason for the variance is then documented in the appropriate section of the LCP, as is the action taken and the outcome.

Religion may be defined as the “shared religious beliefs, values, liturgies and lifestyle of a faith community” (Spiritual Care and Chaplaincy, 2009). Descriptions of spiritual care include “(it is) given in a one to one relationship, is completely person-centred and makes no assumptions about personal conviction or life orientation” (Spiritual Care and Chaplaincy, 2009) and ‘that care which recognizes 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’ (Spiritual Care Matters, 2009).

Kearl notes 75% of Americans felt that should they have 6 months to live, their religion would become more important to them (Kearl, 1989). The World Health Organisation also states that one of the princi-

ples of Palliative Care should be to integrate the psychological and spiritual aspects of patient care (Ashurst, 2007). Different religious groups may require differing rituals at the end of life (Ashurst, 2007).

Approximately 7.9% of the UK population in 2001 were from minority ethnic backgrounds (Faull, Carter & Daniels 2005). Different ethnic, cultural and religious groups may hold opposing views with regards to death and medical treatment (Koenig & Gates-Williams, 1995, Costantini et al, 2006). Communication difficulties may be faced, either through language barriers (Faull, Carter & Daniels 2005) or differing belief and support systems.

To date, little information exists with regards to the cultural, spiritual and religious background of patients receiving specialist Palliative Care (Audit Scotland, 2008). Goal 6, Section 1 of the LCP exists to gather this information. There is a further area of the LCP (Goal 1, Section 1) to record ethnicity. Following initiation of the LCP, the psychological, religious and spiritual support/insight of patients and their carers (relatives) are assessed twice daily (Section 2): new carers may present or the patient's situation may change and 12 hourly assessment of these areas allows for adaptation in the provision of care should this be necessary (NCDAAH, 2006-7).

Figure 1: Example of Goal 6, Section 1 of the Liverpool Care Pathway for the Dying Patient (LCP, MCPI)

<b>Religious/ Spiritual support</b>	<b>Goal 6: Religious/spiritual needs assessed</b>	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	Comatosed <input type="checkbox"/>
	a) with Patient	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	
	b) with Family/other	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	
	Patient/other may be anxious for self/others			
	Consider specific cultural needs			
	Consider support of Chaplain/Religious adviser			
	Religious tradition identified, if yes specify: Church of Scotland	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
	Support of Chaplain/Religious adviser offered	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
	In-house support Tel/bleep no: 81234 Name: Rev. A. N. Other Date/time: 2-4-09 1835			
	External support Tel/bleep no: 01234 567890 Name: Rev. J. Smith Date/time: 2-4-09 1835			
Comments (Special needs now, at time of impending death, at death & after death identified)				
Would like to see own Minister to discuss funeral.				
..				

## Identification of Objective

A successful audit requires identification of a problem or objective. As the above information suggests that religion/spirituality may have a significant impact upon the dying period, it was felt that an appropriate aim would be to audit the assessment and documentation of Goal 6, Section 1 of the Liverpool Care Pathway for the Dying Patient.

The audit plan was discussed in the Hospice Research and Audit Meeting and a proposal was submitted to the Hospice Ethics Committee. Permission to conduct this audit was subsequently granted.

## Standards

Audit standards were discussed with the Marie Curie Palliative Care Institute Evaluations Office in Liverpool (MCPIE). It was felt that although 100% compliance would be the gold standard, this was potentially unrealistic and that no official standards existed. It was noted that the National Care of the Dying Audit – Hospitals (NCDAH) Summary 2006-7 revealed that Goal 6, Section 1 of the LCP was achieved in 34% of patients and 53% of carers (NCDAH, 2006-7).

Strathcarron Hospice had previously audited the LCP internally between April – May 2007 (n=20,

age range 54-84, median age 67, 35% female). 10% of patients had their religious/spiritual needs assessed and 55% were comatose at this point. 20% of relatives had their religious/spiritual needs assessed. The results of this audit were fed back to the Multidisciplinary Team during education sessions.

Audit standards were discussed during the multidisciplinary Hospice Research and Audit meeting and with the Hospice Clinical Effectiveness Co-ordinator. It was accepted that 100% compliance with Goal 6, Section 1 of the LCP may not be achievable as relatives may be absent at the time of LCP initiation etc.

Following these discussions, standards were set at 80% compliance with Goal 6, Section 1 of the LCP

as it was felt that the figures described by NCDAH (NCDAH, 2006-7) and the previous internal audit were too low and that 100% was potentially unrealistic due to factors discussed above. It was felt that 80% was a more realistic and achievable target. In order to facilitate data collection, Goal 6 was divided into more measurable sections and standards were set as follows:

Goal 6.1: 80% of patients have their religious and spiritual needs assessed (not including patients coded as comatose).

Goal 6.2: 80% of patient's families have their religious and spiritual needs assessed.

Goal 6.3: 80% of patients have religious traditions/spiritual needs identified and documented as applicable.

Goal 6.4: 80% of patients are offered the support of a Chaplain/ religious/spiritual adviser.

## Objective

To ensure that 80% compliance with assessment and documentation of Goal 6, Section 1 of the Liverpool Care Pathway for the Dying Patient occurred.

## Audit Methods

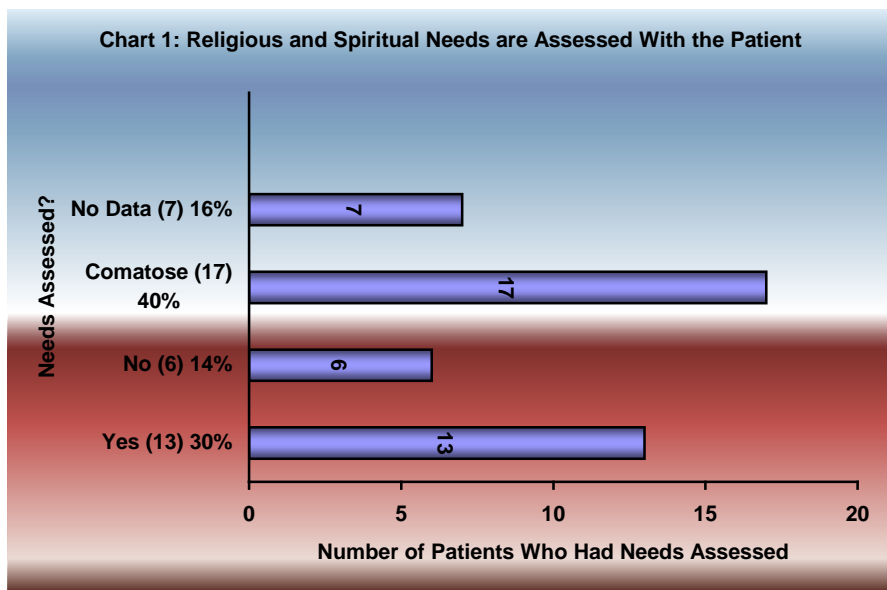
Audit inclusion criteria were all Strathcarron Hospice inpatients commenced on the LCP between 1.6.08 – 31.8.08. With help from the Hospice Clinical Effectiveness Co-ordinator, a list of patients initiated on the LCP during this time period was obtained – details of such patients are automatically entered into an electronic database. Patient notes from the Hospice Records room were obtained and the filed LCP forms were reviewed. Compliance with Goals 6.1 – 6.4 was documented by using a proforma based on Goal 6, Section 1 of the LCP: data was subsequently analysed. A retrospective audit covering a 3 month period (1.6.08 – 31.8.08) was completed, followed by presentation of results to the Hospice multidisciplinary team.

## Results

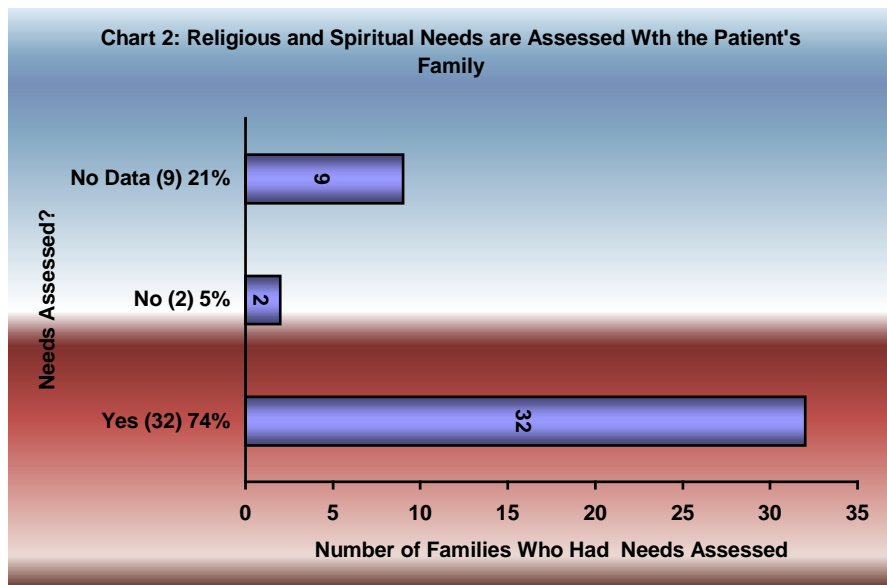
43 inpatients were commenced on the LCP in Strathcarron Hospice between 1.6.08 and 31.8.08. These patients had an age range of 47 – 92 years and a mean age of 66.4 years. 56% were male and

44% were female. 46% of patients had their ethnicity documented: all were variants of Caucasian or British. 42 patients had a primary malignancy and 1 patient had a progressive neurological disorder. The mean duration on the LCP was 3.9 days.

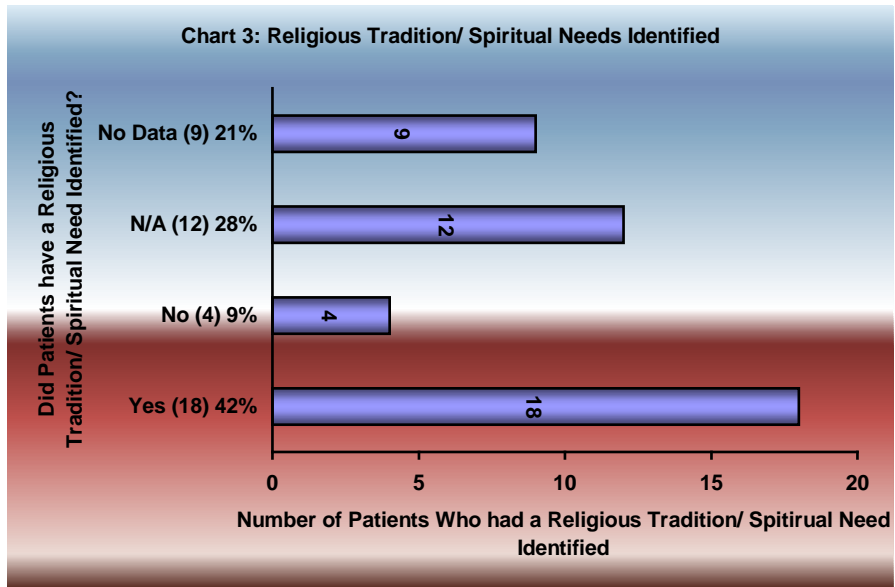
Goal 6.1: Religious and Spiritual Needs are Assessed with the Patient



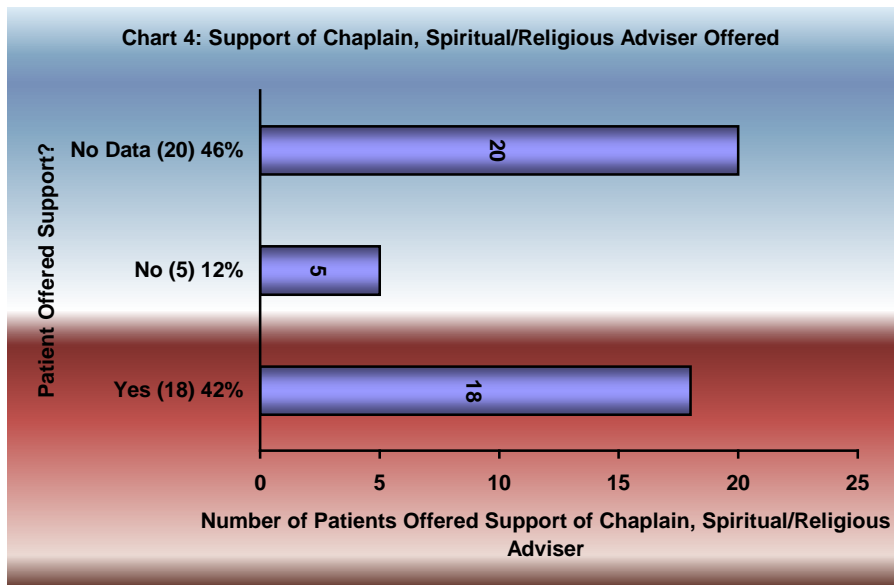
Goal 6.2: Religious and Spiritual Needs are Assessed with the Patient's Family



Goal 6.3: Religious Tradition/Spiritual Needs Identified:



Goal 6.4: Support of Chaplain, Spiritual/Religious Adviser Offered



**Discussion**

Although only 30% of patients were documented as having had their religious and spiritual needs as-

essed, 40% of patients were comatose and unable to hold conversations. The MCPIL suggests that documentation of 'comatose' is a valid assessment for Goal 6.1 (MCPIL, 2009). Many patients commencing

the LCP are likely to be comatose and unable to have their religious/spiritual needs directly assessed with them. The MCPIL excludes comatose patients when calculating the standard achieved, therefore by this method, the standard was achieved in 50% of patients (43 – 17 comatose patients = 26 patients, 13 (50%) of whom had their religious and spiritual needs assessed). 16% of staff did not document any information for this goal. This was an improvement from the previous internal audit, where 10% of patients were documented as having had their religious/spiritual needs assessed and 55% were documented as being comatose – if the 55% of patients who were comatose were excluded from the calculation (in keeping with the MCPIL data presentation), 22% of patients had their religious and spiritual needs documented as having been assessed in the initial audit.

Despite the desired standard of 80% not being achieved, it was encouraging to note that 74% of patients' families had their religious/spiritual needs documented as having been assessed – again, this was an improvement from the previous internal audit where 20% of relatives were documented as having had their religious/spiritual needs assessed. 21% of staff did not document any information for this goal. These results suggested that Hospice staff are more likely to assess religious/spiritual needs with patients' families than with patients themselves, in keeping with NCDAH data (NCDAH, 2006-7).

42% of patients had a religious tradition/ spiritual need identified and documented – this tended to focus on religion and not spirituality. 9% of patients were documented as not having a religious tradition/ spiritual need identified. It was felt that this 9% was a valid assessment as it suggested that the goal had been assessed and that no religious tradition/spiritual needs had been identified. 28% of individuals recorded that it was not applicable to identify a religious tradition/spiritual need, and 21% did not record any data. Reasons for this were further explored in the Hospice Research and Audit meeting.

42% of patients were documented as having been offered the support of a Chaplain or spiritual/religious adviser and 46% of patients did not have any data recorded for this goal. It was felt

that all patients should have been offered the option of internal Chaplaincy support.

Interestingly, all patient LCP progress notes mentioned that the patient was 'agitated' or 'restless' at some point. Reviewing the variance section of the LCP, most patients received analgesia or midazolam as an outcome: few had documented consideration given to the fact that the distress may have been of a spiritual/religious nature.

The core admission section and the main demographic proforma in the multidisciplinary patient notes where religion/spirituality/ethnicity are documented were also reviewed: many patients did not have this information recorded.

The audit was presented at the multidisciplinary Hospice Research and Audit meeting. Discussion amongst the MDT was enlightening and raised several points.

Hospice staff did not necessarily feel comfortable discussing religion/spirituality, particularly at the first patient meeting

The general feeling was that staff might have 'missed the boat' with regards to religion if it was first broached at the time of LCP initiation

Hospice staff felt that religion was easier to document than the less tangible 'spiritual care'

It was felt that spiritual care was often naturally and unconsciously administered by Hospice staff and therefore less likely to be documented

It was generally felt that administering midazolam for distress, whether it be due to breathlessness, spiritual factors etc may be entirely appropriate

Some staff were unsure how to broach spiritual/religious issues: ways in which this might be facilitated were discussed which staff members found helpful

The question "What gives you strength?" was felt to be a good general question to elicit what patients and their families found to be important – it was felt that a patient's family or following a football team might be more important than religion to some individuals and that, if someone were religious, this would come out in conversation.

## **Recommendations for improvement**

Healthcare professionals should be aware that dying patients often have cultural, spiritual and/or religious

needs and that it is important to address these as appropriate

Staff who feel uncomfortable asking these questions/providing this care should be offered help to do so – appropriate reading material might include “Spiritual Care and Chaplaincy” (Spiritual Care and Chaplaincy, 2009), published by the Scottish Government, or “Spiritual Care Matters, An Introductory Resource For All NHS Scotland Staff” (Spiritual Care Matters, 2009) published by NHS Education for Scotland

Religious/spiritual/cultural factors should be ascertained prior to LCP initiation where possible and documented in the multidisciplinary case notes – appropriate places included the ‘Religion and Spirituality’ section in the patient core admission, or the patient demographic sheet

The MCPIL recommends that religion and spirituality should be revisited with patients and their families at the time of LCP initiation (MCPIL, 2009)

Internal Chaplaincy support should be offered to patients and their families

Details for external religious/spiritual advisers should be documented in Goal 6, Section 1 of the LCP

“What gives you strength?” was felt to be a good general question to elicit what helped patients and their families cope with living and dying, and one which staff felt comfortable asking

If relatives were absent at the time of LCP initiation, attempts should be made to undertake a spiritual/religious needs assessment at a later stage as appropriate

Comatose patients should be omitted from calculations when considering achievement of the 80% standard in Goal 6.1 in keeping with MCPIL data

The initial 80% standard for this Goal 6, Section 1 of the LCP should be maintained as it was felt to be a reasonable and achievable standard

The audit cycle should be repeated once recommendations for improvement have been implemented and been in place for several months

## Conclusions

Overall, the repeat audit has shown that assessment and documentation of Goal 6, Section 1 of the LCP in inpatients in Strathcarron Hospice has improved since the previous internal audit, although the desired 80% standard has yet to be met. It was suggested in the internal Hospice Research and Audit

meeting that Hospice staff probably do administer spiritual care but might not always document this. Internal discussion suggested that religion and spirituality were topics which Hospice staff may feel uncomfortable discussing and ways in which this might be facilitated were discussed as above.

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