Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers

LINDA ROSS BA, RGN, PhD and JACKY AUSTIN MBE, PhD, BSc (Hons), RGN

1Reader in Spirituality & Healthcare, Department of Education and Service Delivery, Faculty of Health, Education, Psychology and Sport, University of South Wales, Pontypridd and 2Consultant Nurse, Heart Failure and Cardiac Rehabilitation Services, Aneurin Bevan Health Board, South Wales, UK

Correspondence
Linda Ross
Department of Education and Service Delivery
Faculty of Health, Education Psychology and Sport
University of South Wales
Pontypridd
CF37 1DL
Wales
UK
E-mail: linda.ross@southwales.ac.uk

Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: Implications for nurse managers

Background Spiritual care is an important element of holistic care but has received little attention within palliative care in end-stage heart failure.

Aims To identify the spiritual needs and spiritual support preferences of end-stage heart failure patients/carers and to develop spiritual support guidelines locally.

Method Semi-structured interviews (totalling 47) at 3-monthly intervals up to 1 year with 16 end-stage heart failure patients/carers. Focus group/consultation with stakeholders.

Results Participants were struggling with spiritual/existential concerns alongside the physical and emotional challenges of their illness. These related to: love/belonging; hope; coping; meaning/purpose; faith/belief; and the future. As a patient’s condition deteriorated, the emphasis shifted from ‘fighting’ the illness to making the most of the time left. Spiritual concerns could have been addressed by: having someone to talk to; supporting carers; and staff showing sensitivity/taking care to foster hope. A spiritual support home visiting service would be valued.

Conclusions Our sample experienced significant spiritual needs and would have welcomed spiritual care within the palliative care package.

Implications for nursing management Nurse managers could play a key role in developing this service and in leading further research to evaluate the provision of such a service in terms of its value to patients and other benefits including improved quality of life, spiritual wellbeing, reduced loneliness/isolation and a possible reduction in hospital admissions.

Keywords: heart failure, palliative care, qualitative research, spiritual care, spiritual needs, spirituality

Accepted for publication: 1 March 2013

Introduction

Spiritual care is an important part of health care and features within healthcare policy and guidance internationally (e.g. WHO 2002, 2012), at European level (Equality & Human Rights Commission 1998), and within the United Kingdom (UK) nationally (e.g. Department of Health (DH) 2009a,b, NHS 2012) and
locally (e.g. NES 2009, Scottish Government 2009, Welsh Assembly Government 2010). Spiritual care has been defined as:

‘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 prayer or sacrament, or simply for a sensitive listener’. (NES 2009, p. 6).

There is a growing evidence base demonstrating an association between the spiritual part of a person’s life and their mental and physical health (e.g. Koenig et al. 2012, Walsh et al. 2002, Balboni et al. 2007, Candy et al. 2009, Hollyway & Walker 2009, Koenig 2009) as well as a protective effect on psychological morbidity and quality of life (McClain et al. 2003, Tarakeshwar et al. 2006). There is evidence that the psychological and spiritual domains are distinct but related. Whereas the psychological domain is concerned with affect, cognition, self-esteem and body image, the spiritual domain is concerned with spiritual/religious/personal beliefs, connection, meaning, wholeness and spiritual strength (O’Connell & Skevington 2010). Examination of the range of definitions of spirituality across disciplines involving diverse groups reveals common elements: hope and strength; trust; meaning and purpose; forgiveness; love and relationships; belief and faith; and peoples’ values, morality, creativity and self expression (RCN 2011, McSherry & Ross 2012).

There is an expectation within professional codes of ethics and education guidelines that healthcare professionals, such as nurses, will deliver spiritual care as part of holistic care (e.g. QAAHE 2001, ICN 2006, NMC 2010). Considerable research and scholarly work has been undertaken by nurses exploring how they can address this important part of their role (e.g. Ross 2006, McSherry & Ross 2010, 2012) and professional bodies, such as the Royal College of Nursing, have produced guidance (RCN 2011, 2012). In the field of medicine, a patient’s spiritualidad and how this impacts upon their health is also gaining recognition (Murray et al. 2003, 2005, 2007, Puchalski 2010). Patients also value spiritual care (MacLean et al. 2003, McClain et al. 2003, McCord et al. 2004, Ross 2006).

Based upon this evidence, guidelines now include spiritual and religious care as an essential component of end-of-life healthcare (Marie Curie 2003, NICE 2004). The main focus of these guidelines has been on palliative care of cancer patients rather than on chronic conditions such as advanced heart failure. The Welsh Government stipulates the importance of preventive primary and community-led care and is redesigning services for patients with chronic conditions such as heart failure with a view to meeting their ongoing needs whether physical, psychological or social with the intent of reducing emergency admissions to hospital (Wales Audit Office 2008). Advanced heart failure is a complex syndrome and dying from the condition can be a lengthy and difficult process. It often involves severe exhaustion and prolonged uncertainty for both patients and carers and may bring with it additional psychosocial and spiritual challenges (Basta 2004, Lehman 2006, Park 2008, National Institute for Cardiovascular Outcomes Research 2012). The notion of ‘total pain’, a term originally coined by Saunders (1996), has been applied to the experience of chronic heart failure and includes spiritual pain in which there is a lack of inner peace and personal integrity (Goebel et al. 2009).

In 2004, the DH called for further research on spiritual care of people with end-stage heart failure. Work prior to 2004 and mainly conducted in the USA suggested that spiritual wellbeing may contribute to the overall quality of life in heart failure (e.g. Westlake & Dracup 2001, Beery et al. 2002). American and Australian research since then has focused upon promoting spiritual wellbeing and quality of life in this patient group (Davidson et al. 2007, Larsen 2008, Whelan-Gales et al. 2009) through spiritual coping strategies emphasising the importance of hope (e.g. Davidson et al. 2007) and interventions such as meaning-centred therapies and pastoral counselling (Westlake et al. 2008). Few studies, however, have focused on exploring the spiritual needs and spiritual support preferences of heart failure patients in the UK.

In a study of the total needs of this patient group,spiritual needs and spiritual support services emerged as being important to a sample of heart failure patients/carers prospectively interviewed in Scotland; many were seeking for meaning and purpose in the final stage of life and carers struggled to cope with the suffering of their loved ones (Murray et al. 2004). The opportunity to talk about spiritual issues when offered was welcomed; however, professionals sometimes inadvertently caused spiritual distress by undermining people’s sense of self worth and identity. Unlike those suffering from terminal cancer, people with heart failure experienced fluctuations in spiritual distress until their death (Murray et al. 2007, 2010).

Murray et al.’s (2004) study, however, focused on the total needs of end-stage heart failure patients from which the importance of the spiritual emerged. They
acknowledge that their data specifically related to spiritual needs was limited and, like the DH (2004), recommended a more in-depth exploration of this part of life. We, therefore, focused specifically on the spiritual issues and care needs of end-stage heart failure patients and their carers', rather than their needs in general. We planned to use this information to develop spiritual care guidelines within the palliative care package offered locally. By involving patients/carers directly, the study also responded to local directives [Welsh Assembly Government 2005, Gwent Healthcare NHS Trust 2006 (now Aneurin Bevan Health Board)]. In addition, we also sought to determine if the experience of spiritual need varied by geographical area. We conducted our study in the South Wales valleys which is geographically and economically different from the Edinburgh area where Murray et al. (2004) carried out their study, being predominantly rural and economically poor, with a high proportion of families in social classes IV and V.

In Wales, the death rate from coronary heart disease is greater than the majority of countries in Western Europe (NAW 2001). In 2003, one of our study hospitals in South Wales established a cardiac rehabilitation programme for patients with chronic stable heart failure after the results of a randomised controlled trial conducted by the authors. The results of the study (the first in the UK and winner of British Heart Foundation Excellence Award 2005) showed clinically significant benefits to patients in terms of functional status, distance walked and quality of life compared with standard outpatient care (Austin et al. 2005, 2008). While the multidisciplinary programme included medical input, exercise, dietary advice, education, occupational therapy and psychosexual counselling, the spiritual needs and concerns of patients were not specifically addressed.

Aims

- To identify whether end-stage heart failure [New York Heart Association Class (NYHA) IV] patients and their informal carers (e.g. spouse) experience significant spiritual needs in the context of their overall needs.
- To identify how spiritual concerns vary over the course of the illness.
- To identify how patients/carers perceive that they might be helped and supported in addressing spiritual issues.
- To develop spiritual support guidelines, as part of the palliative care package, for end-stage heart failure patients and their carers.

Data collection and analysis

Design

Recruitment and sample

Ethical approval was obtained from the University of Glamorgan, Aneurin Bevan Health Board and South East Wales Research Ethics Committee in 2006/2007. Seventy-two NYHA IV patients were identified from databases in two hospitals between March and December 2008 by J.A. after receiving permission from the relevant consultant cardiologists. Severe dementia was the only exclusion criterion. Of the 72 patients identified, 15 did not attend their appointments, 13 died and 12 were deemed too unwell on clinical assessment. Twenty-six of the remaining 32 patients accepted information about the study during routine follow-up at the heart failure clinic and 17 agreed to participate. One died before the first interview, giving a sample of 16 patients.

Aims 1–3

Half the sample lived alone (n = 8) and half lived with their informal carer (spouse/daughter, n = 8). Because of the sensitivity of the subject and the heavy involvement of informal carers in looking after a loved one suffering from heart failure, patients living with their carer were given the option of being interviewed with them present; all accepted this offer. Interviews took place in patients’ homes at 3-monthly intervals over a year, between June 2008 and December 2009 (maximum of four interviews). At the first visit, patients completed a demographic questionnaire. They were then interviewed using a semi-structured interview schedule based upon the work of Ross (1997) and Murray et al. (2004) which centred around five areas: impact of the illness; meaning, value and purpose; impact of spiritual needs; who could help; and focus on the future. Written consent was obtained at each visit and subjects were asked if they would like to comment on the analysis of the transcript before the next interview. A total of 50 interviews were conducted (16 first, 15 second, 11 third and 8 fourth) and tape recorded. Three tapes were blank leaving 47 interviews which were transcribed. Each interview was coded and subjected to narrative analysis, as described by Murray et al. (2004). Thus, themes relating to the types of spiritual needs experienced (Aims 1 and 2) and spiritual support welcomed (Aim 3) were identified. The qualitative analysis package ‘Ethnograph’ assisted with this process. Demographic data were scored and entered into SPSS (SPSS Inc., Chicago, IL, USA).
A focus group was held with key stakeholders [from palliative care \((n = 4)\), heart failure \((n = 4)\), chaplaincy \((n = 1)\), parish nursing teams \((n = 1)\)] in 2010 to identify ways of tailoring current care provision to address the spiritual and existential concerns of this vulnerable patient group. Patients who had participated in the interviews (four of whom were still alive) were also invited to attend; one was well enough to do so.

Following the focus group, the four remaining patient participants were approached to ask their views of this intended provision. Three were consulted by telephone; one was in hospital so was unable to take part. They were asked specifically if they would benefit from having someone co-ordinate their care. They were also asked if they would benefit from having someone visit to talk through their spiritual concerns and, if so, who they would like to see (volunteer, chaplain, nurse, psychologist or someone from the heart failure team), how they would like to be contacted (phone call or at a clinic) and when this contact should occur (when first seen at a clinic or when symptoms got worse).

**Results and discussion**

The results are presented and discussed together to minimise repetition. The discussion compares our findings with that of the existing literature as well as highlighting the implications for nurse managers in terms of practice, policy and research.

**The sample**

The average age of the sample was 73 years (range 60–84) and included nine men and seven women. Equal numbers were: married/not married; living with spouse/alone; and living in most/least deprived areas of Wales. Ten patients claimed ‘Christian’ religious affiliation and six of them were practising. The average WHO performance status at first interview was 2.9 where 0 represents unrestricted activity and 4 represents complete disability. Ischaemic heart disease was the main cause of heart failure. The profile of the sample was similar to that of Murray et al. (2004) except our sample had slightly higher WHO performance scores at baseline and half of our sample were still alive at the end of the study which is consistent with the prognosis for the illness [National Institute for Cardiovascular Outcomes Research 2012] compared with a third of Murray’s sample.

**Experience of healthcare and effects of the illness**

Although the focus of the study was on the spiritual part of life, participants had much to say about their experience of healthcare and the impact of the illness on their lives; these findings are reported as they impact upon the whole person and their care experience of which the spiritual is part. Participants particularly valued home visits by \((n = 8, 31\) i.e. eight patients indicated 31 times that they valued home visits) and telephone access to health professionals \((n = 7, 15)\). Distress was caused when care needs were not met \((n = 12, 45)\), by long waiting times \((n = 9, 37)\) and by poor/conflicting/fragmented communication \((n = 6, 33)\). Fatigue/reduced mobility \((n = 14, 78)\), co-morbidity \((n = 13, 64)\), concerns about medication \((n = 14, 32)\), worries about increasing dependence \((n = 12, 44)\) and depression \((n = 11, 22)\) also caused distress. Many expressed frustration at having to fight for the services they felt they needed. The all-consuming nature of the illness \((n = 8, 12)\) was illustrated by one patient:

‘I want a life. I haven’t got one, I haven’t got one at all, so what can you do about that? Can you give me a new life?’.

Murray et al. (2004) similarly reported that heart failure patients talked a lot about their physical needs and practical problems, compared with lung cancer patients.

**Experience of spiritual needs and variation over the course of the illness (Aims 1 and 2)**

Spiritual issues were significant for the sample with all 16 patients/carers struggling with spiritual/existential concerns. These related to six main themes which corresponded with the key concepts of spirituality identified in the literature (e.g. RCN 2011).

**Love & belonging**

Isolation and loneliness was the single greatest issue \((n = 16, 144)\); some patients saw virtually no-one from one interview to the next and came to value the researcher’s visits. It was of greater concern than any other physical or non-physical symptom and was similarly a major theme emerging from Murray et al.’s (2004) work. As one gentleman said:

‘I don’t meet people. The only people I see now is my carers. Otherwise I don’t see a soul. I don’t see anybody.....Oh very very lonely. Very very lonely’.
The geography of the South Wales valleys meant that most patients could not walk anywhere because of the steep slopes. As one carer said:

‘. . . we’re up on top of a hill I can’t physically push him down that hill or up it in a wheelchair because he’s 13 stone and I just can’t do it. So the only way I can get him out is either by ambulance or if my son is home’. Electric wheelchairs were unaffordable for most and houses were too small to accommodate them, highlighting the poverty in this region. The need for love and belonging through relationships was frequently mentioned by participants (n = 14, 84), and links with the isolation and loneliness felt by this group. For those who had family, these relationships were highly valued, a finding which concurs with Murray et al. (2004). For many others, particularly those living alone, broken or difficult relationships with family and friends (n = 7, 44) was a cause of anxiety and sometimes regret (n = 5, 7). Tension existed between patients and carers: on the one hand patients wanted to stay independent (n = 9, 28) and feared being a burden to their loved ones (n = 10, 21) whereas carers talked about the strain of caring and being over protective (n = 8, 48). The struggle of carers was similarly highlighted by Murray et al. (2004).

Hope and coping
The majority of patients coped with their illness by maintaining a fighting spirit, keeping busy (n = 11, 31) and trying to ‘make the most of it’ (n = 6, 10). Many stayed hopeful by promising themselves treats (such as a meal out or trip to a concert) or by keeping dreams alive (n = 10, 33). These ‘dreams’ or aspirations were not always realistic (e.g. one house bound patient talked of obtaining portable oxygen to enable him to use public transport to reach a steam train he’d always wanted to ride on some hundred miles from where he lived) but seemed to serve to keep hope alive. Others put great hope in living as normal a life as possible and looked to new treatments/cures (one even talked about a heart transplant) to provide this (n = 9, 20). It is important for health care staff to note the influence they have on a patient’s state of hope by what they say, especially in the light of emerging evidence from descriptive observational studies demonstrating the positive impact of hope on cardiovascular outcomes (e.g. Davidson et al. 2007). The following quote illustrates how hope can be taken away with a few (sometimes careless) words:

‘It’s a bit of a downer really, I haven’t seen this doctor before . . . I said well it makes you feel better (referring to doing gentle exercise). . . he said “well why do it, there’s nothing there to build on, you’ve got nothing at all”. I didn’t need that at the time you know. I needed somebody to build me back up’.

Meaning and purpose
Some patients were struggling to make sense of their illness, asking why this had happened to them (n = 6, 13) and four admitted to having difficulty accepting their illness. Two blamed themselves for becoming ill. These findings are similar to that of Murray et al. (2004) except patients in our study did not see their illness as punishment for wrongdoing in their past life, but rather as a result of ignoring advice. A quarter of patients felt that they no longer served any purpose, seeing themselves as useless and of no value, which again concurs with Murray et al.’s (2004) findings. For example one patient said:

‘I feel that my usefulness on earth is finished now. I’m neither use nor ornament now really’.

However, six gained a sense of purpose through their work in the local community which they struggled with increasingly. The way in which local people supported these patients in continuing in their roles, even when their contribution became significantly reduced, is encouraging.

Faith, belief and existential issues
The subject of death and dying featured in many of the interviews and patients were aware of being on ‘borrowed time’ (n = 9, 17), some having been resuscitated previously. For example, one patient said:

‘I’ve had more lives than a cat in the last 26 years. I should have been dead more times than a cat. I’ve had more than 9 lives’.

Patients did not seem to be afraid of death (n = 7, 13) and in some cases were actively wishing for it. The process of dying and whether they would die alone was of more concern. Six patients were practising a religious faith. The importance of this faith became evident for five patients (who mentioned it 21 times) through the interviews and concurs with Murray et al.’s (2004) findings. Those with no religious faith were aware of the transcendent in their lives, for example by stating an awareness of a ‘guardian angel’ looking after them (n = 4, 9), coincidences (n = 4, 5) which made them
think that perhaps a greater force might be at work, and through pondering eternal issues \( (n = 2, 3) \).

These findings highlight the importance of faith leaders from local churches supporting people with a religious faith living at home as they try to cope with their illness. End-stage heart failure is characterised by frequent hospital admissions, therefore, hospital chaplains have an important role in supporting those with a faith as well as those with no faith while in hospital. It is of concern, therefore, that most patients had never been asked if they would like a visit from the hospital chaplain on admission. Further, patients with no religious faith had no-one to talk to about their existential concerns once discharged home. The hospital chaplain was not available to them and they did not belong to a faith community, so they were struggling with these issues and concerns alone further exacerbating their sense of isolation and loneliness. This ‘lone’ struggle, often lasting many months, was similarly reported by Murray et al. (2004) and highlights the potential value of pastoral counselling (Westlake et al. 2008) in enhancing spiritual wellbeing and in reducing depression (Whelan-Gales et al. 2009).

The future and variation in spiritual needs over the course of the illness

At first many patients were determined to fight their illness and were optimistic of an improvement/cure. Over time, however, as their physical condition deteriorated, they became more resigned to the fact that things were not going to improve \( (n = 12, 27) \). The emphasis shifted from ‘fighting’ to making the most of the time left \( (n = 6, 10) \). Many feared loss of independence, dignity and control and three described the future as grim:

‘Grim, grim, really grim. I can’t see there being any improvement at all. I’m waiting for a portable unit to get out for a bit of a walk’.

**Spiritual help/support (Aim 3)**

Many suggestions were given for improving care in general. These are listed in Box 1 and provide valuable insight for nurse managers who are looking to commission/improve local heart failure health services. The suggestions may also be useful to nurse managers running similar services within the UK and abroad who can use this information as a check list when considering ways of enhancing their own service provision.

The main focus of our study was on identifying things that could be done to support patients/carers in addressing spiritual issues specifically. These are summarised in Box 2. As in Box 1, these have implications for nurse managers locally, nationally and internationally who are seeking to enhance heart failure service provision and ultimately meet the holistic needs of the patients and families they serve.
Developing spiritual support guidelines and services (Aim 4)

It was evident from our research that spiritual concerns were not being fully addressed by current heart failure service provision at the hospitals in our study. We, therefore, held a focus group with key stakeholders and consulted with patients to explore how this gap in service provision might be addressed.

The outcome of these consultations highlighted the need for patients to talk to someone who has the time to listen, about their spiritual and existential concerns, particularly in relation to existence, death and the afterlife, and also for company to ameliorate their sense of isolation and loneliness. The consensus was that a spiritual support home visiting service would be valued, especially by patients living alone and at the point where symptoms had deteriorated. Patients would prefer a nurse or someone from the heart failure team (rather than a chaplain, psychologist or volunteer from the general public) to provide this service. Nurse managers may consider innovative ways in which such services could be developed within their own locality. We are presently seeking funding to do this.

Limitations

The study was limited by its size, therefore, findings cannot be generalised beyond the sample or geographical area. It does, however, have the potential to improve service provision locally. The small sample size may also have introduced an element of bias in that the views and experiences of the intended population may not have been fully captured. The inclusion of carers in half the interviews may have introduced bias but to exclude them would have resulted in an incomplete picture of the spiritual issues/concerns being captured as the patient and their carer were so intricately entwined in coping with the illness together. Every qualitative study has an element of researcher bias. This was minimised by: attempting to conduct the interviews in an open a manner as possible; having a proportion of the transcripts re-analysed by a third party unconnected with the study to check for reliability of coding; involving a multidisciplinary steering group (11 staff representing different disciplines, levels including patients) in discussion of the evolving themes; and giving participants the opportunity to comment on the analysis and to confirm meanings thus confirming accuracy and strengthening the trustworthiness of the research.

Conclusions and implications for nurse managers

The DH called for further research on spiritual care for end-stage heart failure patients. Our findings concur with and add to the current body of knowledge in this field. Spiritual issues were significant for the patients/carers included in this study but were not adequately provided for within the current palliative care package. The actual experience of spiritual needs seems to be fairly consistent across different geographical areas in this patient group; our findings in Wales were similar to those in Scotland (Murray et al. 2004). It would seem that nurse managers have a key role to play in enhanc-
ing heart failure service provision by placing greater emphasis on spiritual care which this patient group identified as being important to them. Although our findings are limited, there are indications that managers can do this in a number of ways. They can, for example, take the lead in fostering stronger links with hospital and community chaplaincy teams who can offer the spiritual support patients and their families need, thus augmenting the support already provided by the multi-disciplinary team. They can also take the lead in ensuring that spiritual issues are included as part of the admission and care planning process and that nurses receive the training needed to affect this. They are also in an ideal position to take the lead in further research to evaluate the provision of such a spiritual support service in terms of its value to patients and to determine any added benefits, as called for in a recent Cochrane review (Candy et al. 2009), such as improved quality of life, spiritual wellbeing and reduced loneliness/isolation, depression and anxiety. Such research findings would provide them with the evidence needed to influence change in healthcare policy for the benefit of the patients they care for.

Acknowledgements

We would like to thank the patients and their carers who participated in this study. We are grateful to Consultant Cardiologists Drs Stephen Hutchison and Nigel Brown and staff for identifying patients.

Source of funding

This work was supported by the Nevill Hall Thrombosis & General Research Fund, the Cardiology Charitable Fund and the University of Glamorgan (now University of South Wales). The work relating to Aim 4 was funded by the University of Glamorgan Strategic Insight Programme for HEFCW Collaborative Third Mission Fund.

Ethical approval

Ethical approval was granted by South East Wales Research Ethics Committee (07/WSE04/21), Aneurin Bevan Health Board, and the University of Glamorgan.

References


Nursing & Midwifery Council (2010) Standards for Pre-registration Nursing Education. NMC, London.


Royal College of Nursing (2011) Spirituality in Nursing Care: A Pocket Guide. RCN, London.


学霸图书馆

www.xuebalib.com

本文献由“学霸图书馆-文献云下载”收集自网络，仅供学习交流使用。

学霸图书馆（www.xuebalib.com）是一个“整合众多图书馆数据库资源，提供一站式文献检索和下载服务”的24小时在线不限IP图书馆。

图书馆致力于便利、促进学习与科研，提供最强文献下载服务。

图书馆导航：

　图书馆首页　文献云下载　图书馆入口　外文数据库大全　疑难文献辅助工具