Title of Article:

Knowledge and Attitudes of Cardiac Nurses of a Palliative Care Approach in Heart Failure.

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Abstract

Applying the principles and practice of a palliative care approach can enhance quality of life of patients suffering with heart failure yet many nurses misunderstand the role of palliative care.

Aim: This study examined the knowledge and attitudes of cardiac nurses of a palliative care approach when caring for heart failure patients.

Method: Two validated questionnaires were used to examine the knowledge and attitudes of 102 nurses in three Irish university hospitals.

Results: 76 nurses responded (75%) and the study found that there was limited overall knowledge but positive attitudes to palliative care. A positive correlation was identified between higher knowledge scores and positive attitudes, indicating that those with greater knowledge of palliative care demonstrated more favourable attitudes to caring for dying patients.

Conclusion: Addressing the palliative care needs of heart failure patients requires education and training and this study identified specific educational needs in pain and symptom control and communication skills.

Key words: palliative care, heart failure, knowledge, attitudes, cardiac nurses

Introduction

Heart Failure (HF) is a common condition with a prevalence rate of 1-2% of the overall population, rising to 10% of those aged over 75 years of age. Over 10,000 new cases of HF occur annually in Ireland and it is one of the most common reasons for emergency hospital admission (Irish Heart Foundation, 2002). Stewart et al, (2001) found that life expectancy for patients with chronic HF is worse than for nearly every common cancer. Despite this poor prognosis, the majority of patients who die from HF seldom have access to palliative care (O'Leary and Tiernan, 2008).

A number of studies have highlighted that many HF patients have unmet needs, such as symptom management and psychosocial concerns including social isolation and lack of emotional support (Murray et al, 2002; Pantilat & Steimle, 2004; O'Leary et al, 2009). There is also evidence that HF patients can benefit from a palliative care approach to symptom control and quality of life issues (Evangelista et al, 2012). In fact, HF experts recommend that palliative care should be integrated through all stages of HF care as it is a supportive intervention for both patients and families (Hupcey et al, 2009; Jaarsma et al, 2009). The reality remains, however, few HF patients receive any palliative care services (O'Leary & Tiernan, 2008). Lack of knowledge and misconceptions about palliative care have been reported among HF specialists with Hupcey et al (2009) noting that both doctors and nurses in specialised HF centres believed that introducing palliative care was synonymous with pre-death care.

Inevitably, all nurses, regardless of level of training or area of specialty, will be involved with patients at end-of-life and will play an essential role in providing hands-on care. They act as advocate, liaison and translator between physician, family and patient in relation to the end-of-life decision making process (Hopkinson et al, 2003). However, many nurses feel under skilled and inadequately prepared for providing this aspect of end-of-life care (Bloomer et al, 2013). The situation is exacerbated as care of the dying can take less priority when nurses are also caring for acutely ill patients (Nordgren & Olsson, 2004).

Providing good end-of-life care not only requires skill and knowledge but also an appreciation of the importance and appropriateness of a palliative care approach within the acute care setting. As the care of HF patients remains predominantly the

responsibility of cardiology staff, this study examined the knowledge level and attitudes of cardiac nurses of a palliative care approach when caring for HF patients.

Methods

Research design

This study used a descriptive cross-sectional design to address the research question. Two self-administered questionnaires were used to quantify both palliative care knowledge and attitudes to caring for the dying and their families. A demographic questionnaire was also included.

Setting and sample

Three large university hospitals in the Republic of Ireland were the setting for this study. These hospitals have active national HF programmes as well as providing specialist palliative care services. A convenience sample targeted all registered nurses working within a cardiology ward or coronary care unit (CCU) environment, reflecting the fact that HF patients are predominantly cared for in these areas.

Instruments

The data collection method was two well established self-report questionnaires, both of which have been used previously in international studies (Brajtman et al, 2007; Ronaldson et al, 2008; Autor et al, 2013). Permission for the use of the questionnaires for the purpose of this study was granted by the authors and the questionnaires were used without modification. Additionally some demographic data was gathered (Table 1) which is important in order to describe and compare the study sample (LoBiondo-Wood & Haber, 2010).

The first questionnaire selected was the Palliative Care Quiz for Nursing (PCQN) developed by Ross et al (1996). The authors developed this tool to provide data about the palliative care knowledge levels of non-specialist participants and suggested it could be used to stimulate discussion about palliative care nursing and identify any participant misconceptions regarding palliative care. The PCQN is a 20 item test of knowledge where answers are given as “true”, “false” or “don’t know”. . The PCQN has the benefit of being readily administered and quickly completed by participants as well as being easily scored by a researcher.

The second questionnaire chosen was designed to examine nurses' attitudes towards caring for dying patients and their families. The Frommelt Attitude Toward Care of the Dying (FATCOD) scale was designed by Frommelt (1991). This is a 30 item tool which uses a 5-point Likert Scale ranging from 'strongly disagree' to 'strongly agree'. Two thirds of the items identify attitudes towards dying patients (person centred care) and one third of the items identify the attitudes towards patients' family (family centred care).

Both questionnaires have a proven record of reliability (Frommelt, 2003; Ronaldson et al, 2008). Ross et al (1996) developed the PCQN in conjunction with palliative care experts and demonstrated the reliability of the PCQN using both a test-retest procedure and the Kuder-Richardson formula 20 (KR-20). The testing reported high internal consistency reliability for the PCQN. Frommelt's original study (1991) using the FATCOD scale demonstrated reliability through a test-retest procedure.

Data analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to present the participants demographic data and knowledge and attitudes scores of the study sample. Inferential statistics were used in order to draw conclusions about the sample. A one-way analysis of variance (ANOVA) was used in order to compare the mean scores of three or more groups followed by post hoc pair-wise comparisons when ANOVA revealed significant differences. T-tests were used to measure differences in means between two groups.

Ethical considerations

Ethical approval for this study was granted by the Research Ethics Committee of Trinity College Dublin and by the ethics committees at each hospital. Participants were informed of the purpose of the study and given instructions for completing the questionnaires. Participation was voluntary and anonymity was guaranteed.

Data Collection

Data were collected between November and December 2014. 77 out of the 102 nurses returned the questionnaire, one response was spoiled and was excluded from analysis, giving an overall response rate of 75%.

Results

Participant demographics

Table 1 presents the demographics for all respondents. The respondents were predominantly female (95%) with a mean age of 36 years. 65% (n=49) of the respondents were working in CCU, while the remaining 35% (n=26) were working on a cardiology ward. When asked if they had previous education on death and dying, 16% (n=12) nurses reported having never received any education on this subject while 18% (n=14) of respondents reported having attended a course on death and dying previously. The majority of respondents (62%) had not taken a specific course but material on the subject had been included on other courses they had undertaken. Of the 76 nurses who participated in the study, 92% stated they had previously cared for terminally ill patients while 7% (n=5) stated they had no experience in caring for terminally ill patients.

PCQN analysis: What is the knowledge of cardiac nurses of palliative care?

Knowledge of palliative care, as measured by the PCQN, incorporates three theoretical categories within palliative care namely: understanding of principles and philosophy of palliative care, pain and symptom management and psychosocial and spiritual care. The score ranges from 0 to 20 with higher scores indicating greater levels of knowledge.

The analysis of the total scores on the PCQN revealed a mean score of 10.7 (standard deviation (SD)=2.92) indicating a limited overall knowledge of palliative care. The highest score achieved was 17/20 and the lowest was 4/20. Table 2 presents the results of the responses analysed by percentage correctly answered. Question 4 (Adjuvant therapies are important for managing pain) had the highest percentage of correct answers (93%) whereas Question 6 (During the last days of

life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation) had the lowest (21%).

FATCOD analysis: What are cardiac nurses' attitudes to caring for dying patients and their families?

Attitudes towards caring for dying patients and their families were measured using the FATCOD. Each of the 30 items on the FATCOD is scored on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The overall score can therefore range from 30 to 150 with a higher score indicating more favourable attitudes. The mean total FATCOD score was 122 (SD=11.61, range 92 to 149), representing an overall positive attitude to caring for dying patients and their families. Mean scores were obtained for each item. The item that obtained the highest mean score was "Nurses should permit dying persons to have flexible visiting schedules" at 4.59/5. The item with the lowest mean score was "I would be upset when the dying person I was caring for gave up hope of getting better" at 3.30/5. Table 3 presents the four highest and lowest items mean scores representing the items with the most positive and least favourable attitudes.

Comparison to international studies

The use of both the PCQN and the FATCOD in a variety of different nurse settings in previous international studies allowed for useful comparisons to be made. Table 4 shows PCQN mean scores compared to the mean score in this study of 10.7. Similarly the mean score of the FATCOD scale of 122 compared to other studies is shown in Table 5.

Inferential statistics

Inferential statistics were used to establish whether differences or associations exist between sets of data. In this study, data were analysed by means of cross tabulation to identify the potential relationship between each demographic variable and the knowledge and attitudes of the respondents. When a relationship was suspected, correlation analysis was undertaken to explore the potential significance of this relationship. Place of work, age of respondent and highest degree attained was each found to have significant association with both knowledge and attitudes of the respondents. The overall findings indicated that while cardiac nurses have limited

knowledge of palliative care, they demonstrate positive attitudes towards caring for dying patients. Notwithstanding this, a key finding of this study was a positive correlation between high scores on the PCQN and on the FATCOD (Pearson $r=0.55$, $P<0.001$), indicating that those with increased levels of knowledge of palliative care demonstrate more positive attitudes to caring for dying patients.

This study found that nurses working in CCU had more knowledge and more favourable attitudes than those working on a cardiology ward. Nurses with H.Dip./Other as their highest level of education scored the highest in both the PCQN and the FATCOD. While the six respondents with a Master's degree did not demonstrate higher scores, they did not specify in which area they had specialised. While the mean age of respondents was 36 years, nurses in the age group of 46+ years were found to have the most knowledge and displayed the most positive attitudes.

Discussion

Palliative Care Knowledge

THE WHO (2002) definition of palliative care includes the principle that palliative care is applicable early in the course of illness in conjunction with other therapies intended to prolong life. Despite being in place for over a decade, this principle is neither widely known nor understood within a HF context. As palliative care still tends to be associated with end-of-life care, the term 'supportive care' may be a more acceptable term for HF patients and healthcare professionals alike (Fadul et al, 2009).

One of the most common misconceptions relating to palliative care within HF is the belief that the philosophy of palliative care is incompatible with that of aggressive management and this is perhaps the greatest challenge to ensuring the integration of a palliative care approach into HF management (Gott et al, 2011; Kavalieratos et al, 2014). This study confirmed this misconception with over three quarters of respondents believing, incorrectly, that the philosophy of palliative care was incompatible with that of aggressive treatment. Kavalieratos et al (2014) also found that clinicians on the whole do not recognise that palliative care need not be prognosis dependent but can be provided alongside life prolonging treatment. There

is no conflict between palliative care and active management approaches; one does not commence where the other ends. Instead a palliative care approach should be integrated throughout the illness trajectory from time of diagnosis. This early integration is essential due to the high rate of sudden death and the unpredictable disease trajectory of HF.

Al-Qurainy et al (2009) states that almost all patients in their final stages of life are symptomatic and require medication to improve symptom control. Symptom control is a crucial part of caring for HF patients (Blinderman et al, 2009), yet this study displayed an overall lack of knowledge of pain and symptom management among cardiac nurses, with just 54% correctly responding in this category of the PCQN. This represents a significant knowledge deficit which needs to be addressed through further essential education if pain and symptom management in HF patients are to be proactively treated.

The majority of patients with palliative care needs in an Irish hospital setting are cared for by generalists with only a minority of patients, primarily cancer patients, accessing specialist palliative care services (O'Leary & Tiernan 2008). Therefore it is imperative that these generalists possess basic palliative care knowledge in order to comprehensively address their patients' needs.

Attitudes to caring for dying patients and their families

As the majority of deaths in Ireland occur in acute hospitals or other care settings (McKeown et al, 2010), care of dying patients and their families is generally provided by nurses who may not have education in this sensitive and complex area. In this study 92% of respondents indicated they had previously cared for dying patients yet only 18% had undertaken a course on death and dying. While palliative care is concerned with end-of-life care, this is only one aspect of the broad spectrum of palliative care practice. This study explored cardiac nurses' attitudes to caring for dying patients and their families as caring is universally recognised as one of the core values of the nursing profession.

One of the statements that nurses in this study most strongly agreed with was that providing nursing care to the dying is a worthwhile learning experience, reflecting the overall positive attitude that this study found. However, 23% of respondents were

unsure or agreed that if a patient asked if they are dying, it was best to change the subject to something cheerful. This negative attitude most likely represents the inexperience of respondents in dealing with difficult conversations. In fact this study identified communication as an ongoing challenge for respondents with nearly one third of nurses indicating they would be uncomfortable talking about impending death with dying patients. This finding is consistent with other studies which also identified nurses' difficulty in discussing end-of-life issues with their patients in non-specialist situations (McDonnell et al, 2002; White et al, 2014). Inadequate training in engaging in difficult conversations has previously been identified as the biggest factor preventing nurses from engaging such conversations (Wotton et al, 2005). Communication with HF patients has been described frequently as "inadequate" whereas good communication with patients is considered a pre-requisite in palliative care (Ward, 2002). Equipping cardiac nurses with the skills and techniques for good communication in end-of-life situations should therefore be included in any educational initiative.

The FATCOD scale measures attitudes to caring for both patient and family. This extension of care towards the family is a central tenet of the philosophy of palliative care (WHO, 2002). In this study 87% of respondents believed that nursing care for the patient's family should continue throughout the period of grief and bereavement. In addition 97% of respondents agreed that families need emotional support to accept the behaviour changes of the dying person. Within the critical care area it can be challenging to extend this level of care to families, yet this study demonstrates how strongly nurses see their role in not only caring for their patients but also for the patient's family. Family members of HF patients are often under considerable strain and require support, a problem exacerbated by the fact that family members are often elderly spouses (Selman et al, 2007). Interestingly, despite the strongly held belief in caring for the patient's family, 34% of respondents agreed or were unsure whether family members staying close to a dying person often interferes with the professional's job with the patient.

In a seminal study examining end-of-life care, Lynn et al (1997) found that while dying patients may have wished for comfort care, many continued to receive aggressive life sustaining treatment until their death. More recently, Lingard et al (2013) reported that HF patients had fewer choices regarding end-of-life care

compared to cancer patients. In this study 93% of respondents agreed or strongly agreed that a dying person should be allowed to make decisions about their physical care indicating that cardiac nurses have a clear understanding of the importance of keeping the patient at the centre of their care. As cardiac nurses are the healthcare professionals who provide the majority of care for HF patients, they are most likely to “know the patient” and understand their wishes and thoughts. They are therefore in a unique position to understand and advocate for their patients and their families. While in the biomedical model of care physicians are traditionally responsible for decision making at end-of-life, the palliative model of care includes the patient and family in this decision making process (Jaarsma et al, 2009).

The recommendation of the Department of Health & Children (2010) is for the inclusion of palliative care principles in routine practice. However the findings of this study indicate there is a need for further education in palliative care for cardiac nurses. With appropriate training and education, it is possible that cardiac nurses could meet many of the palliative care needs of the patients and families within their care.

Limitations

There are limitations in this study which warrant consideration. This study was undertaken in university hospitals, each of which has designated palliative care teams. Having access to specialists can reinforce certain misconceptions about whose responsibility it is to provide palliative care (Gott et al, 2011). Had this study included hospitals without specialist palliative care, it may have been possible to explore this possibility.

This study was carried out using questionnaires and it is widely known that self-report methods may result in falsely positive responses (Lange et al, 2008). Additionally while the questionnaires have been used in previous international studies, there are no published cut off values for high and low scores, which leaves scoring open to interpretation.

Recommendations

The identified lack of relevant knowledge poses a barrier to the delivery of high quality holistic care to HF patients and their families which incorporates a palliative

care approach. Therefore an appropriate starting point for any further education for cardiac nurses is on the core philosophy and principles of palliative care, with an emphasis on the fact that the philosophy of palliative care is indeed appropriate and compatible with active HF management. With this proper understanding of the role of palliative care there is a significant probability that the unmet palliative care needs of HF patients can be addressed.

Such educational initiatives on the philosophy and principles of a palliative care approach should be combined with specific clinical education, especially in relation to pain and symptom management and communication skills, both of which were identified as specific needs. These identified learning needs concur with findings from previous studies that highlighted communication and managing signs and symptoms as key educational themes (Davidson et al, 2004; Espinosa et al, 2010). Educational strategies tailored to cardiac nurses should achieve maximum impact recognising the positive attitudes demonstrated in this study.

In addition to traditional educational initiatives, techniques which encourage self-evaluation and reflection should be considered (Georges et al, 2002). This approach will value and utilise the experience and opinions of cardiac nurses and enable them to develop confidence in their ability to care well for their patients. Such an approach would also address misconceptions identified in this study in relation to the risk of burnout from providing a palliative care approach.

Conclusion

Palliative care is based on a number of principles and aims to provide relief from pain and physical symptoms and to incorporate psychosocial and spiritual aspects of care. Adopting a palliative care approach in HF management can enhance the patient's quality of life and help patients to live as well as possible until their death. The increasing number of patients with HF will lead to increasing exposure to end-of-life care for nurses working in the acute care setting. While the inclusion of a palliative care approach into acute care nursing does pose challenges, it also has the potential to improve care for patients and their families while simultaneously developing and enriching nursing practice.

It is widely acknowledged in the literature (Selman et al, 2007; Jaarsma et al, 2009) and accepted for some time by the Irish Department of Health & Children (2001) that, in order to provide the best possible care to patients with HF, it is essential to adopt a palliative care approach. Recognising that it is unfeasible for palliative care specialists to see all end-stage HF patients, Davidson et al (2004) proposed equipping and empowering nurses with appropriate knowledge and education as a practical solution.

Addressing the palliative care needs of HF patients requires cardiac nurses to understand the fundamentals of palliative care. If palliative care can be more broadly understood as a philosophy or approach to care, there is a greater likelihood that the unmet needs of HF patients will be addressed. This study identified specific educational needs in pain and symptom control and communication skills for cardiac nurses.

The positive attitudes demonstrated by the cardiac nurses to a palliative care approach will be instrumental to improving care in HF. Nurses are highly motivated to provide the best care possible for their patients and should, with appropriate education and support, be able to champion a palliative care approach in caring for their HF patients.

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Key Points

- This study examined the knowledge and attitudes of cardiac nurses to a palliative care approach in heart failure.
- The findings indicated that there was limited overall knowledge of palliative care.
- Knowledge deficits in pain and symptom control and communication skills were identified.
- Cardiac nurses demonstrated positive attitudes to caring for dying patients and their families.
- Nurses with greater knowledge of palliative care demonstrated more favourable attitudes to caring for dying patients.
- The positive attitudes will be instrumental to improving palliative care in heart failure.

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Table 1: Demographic characteristics of study participants (n=76)

Variable	n	%
Age		
21-27 years	17	22.3
28-35 years	18	23.7
36-45 years	29	38.2
46 years+	12	15.8
Gender		
Male	3	3.9
Female	72	94.7
Not Answered	1	1.3
Place of work		
Coronary care Unit	49	64.5
Cardiology	26	34.2
Not Answered	1	1.3
Highest Degree held		
Registered General Nurse	25	32.9
Higher Diploma/Other*	15	19.7
Batchelor's Degree	30	39.5
Master's Degree	6	7.9
*Hospital certificate in Cardiac Nursing		
Previous education		
Took a course on death and dying previously	14	18.4
No specific course but material on the subject was included on other courses	47	61.8
No information on death and dying	12	15.8
Not Answered	3	3.9
Previous experience in dealing with terminally ill		
I have cared for terminally ill patients previously	70	92.1
I have had NO experience caring for terminally ill patients	5	6.6
Not Answered	1	1.3

Table 2: Results of responses to the PCQN (sorted by % correctly answered)

	True / False	% Correct
Adjuvant therapies are important in managing pain	T	93%
Individuals who are taking opioids should also follow a bowel regime	T	91%
The provision of palliative care requires emotional detachment	F	76%
Manifestations of chronic pain are different from those of acute pain	T	71%
The extent of the disease determines the method of pain treatment	F	63%
Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration	F	61%
Men generally reconcile their grief more quickly than women	F	59%
The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate	F	59%
It is crucial for family members to remain at the bedside until death occurs	F	51%
The pain threshold is lowered by anxiety or fatigue	T	51%
During the terminal stages of illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea	T	50%
The use of placebos is appropriate in the treatment of some types of pain	F	49%
Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	F	47%
Morphine is the standard used to compare the analgesic effect of other opioids	T	46%
Suffering and physical pain are synonymous	F	45%
In high doses, codeine causes more nausea and vomiting than morphine	T	43%
The accumulation of losses renders burnout inevitable for those who seek work in palliative care	F	42%
Pethidine is not an effective analgesic in the control of chronic pain	T	38%
The philosophy of palliative care is compatible with that of aggressive treatment	T	24%
During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation	T	21%

Table 3: Items from the FATCOD with the four highest and lowest mean scores.

	Mean
Nurses should permit dying persons to have flexible visiting schedules.	4.59
It is beneficial for the dying person to verbalize his/her feelings.	4.51
Families need emotional support to accept the behaviour changes of the dying person.	4.50
Giving nursing care to the dying person is a worthwhile learning experience.	4.47
Family members who stay close to a dying person often interfere with the professional's job with the patient.	3.58
Death is not the worst thing that can happen to a person.	3.46
I would be uncomfortable talking about impending death with the dying person.	3.38
I would be upset when the dying person I was caring for gave up hope of getting better.	3.30
<i>Individual item range = 1 to 5 where 5 represents the most positive attitudes.</i>	

Table 4: PCQN mean scores in international studies

	Mean Score	Population (n)	Cohort	Country
Autor <i>et al</i> , (2013) - of which HF nurses	13.5 12.7	143 43	HF, Intensive Care, & Oncology nurses	USA
Brajtman <i>et al</i> , (2007)	12.3	58	4th year nursing students	Canada
Ford & McInerney (2011) - of which nurses	10.0 12.3	116 48	Residential aged care workers	Australia
Ronaldson <i>et al</i> , (2008) - of which nurses	8.7 11.7	97 36	Residential long term care workers	Australia
Knapp <i>et al</i> , (2009)	10.9	279	Paediatric nurses	USA
Choi <i>et al</i> , (2012)	9.0	368	Oncology, Intensive Care, & general nurses	South Korea

Table 5: FATCOD mean scores in international studies

	Mean Score	Population (n)	Cohort	Country
Dunn <i>et al</i> , (2005)	130	58	Oncology and Medical / Surgical nurses	USA
Frommelt (2003) - Pre education - Post education	118 130	115	Undergraduate nursing students	USA
Brajtman <i>et al</i> , (2007)	129	58	4 th year nursing students	Canada
Braun <i>et al</i> , (2010)	126	147	Oncology nurses	Israel
Ford & McInerney (2011)	119	116	Residential aged care workers	Australia