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Abstract

Aims This study aimed to examine the palliative care knowledge and attitudes of nurses working in care of older people settings in one rural region in Ireland.

Design: A cross-sectional survey design was used combining two questionnaires: the Palliative Care Quiz for Nurses (PCQN) and the Thanatophobia Scale (TS).

Results: Sixty one nurses completed the questionnaire (a response rate of 63%). There was a significant correlation found between level of knowledge and attitudes towards palliative care ($p=0.007$), highlighting that as participants' level of palliative care knowledge increases, attitudes become more positive. While palliative care training did not impact on the mean overall scores in this study, there was a significant difference in the PCQN scores of those who had completed the European Certificate in Essential Palliative Care (ECEPC) compared with those who had information sessions within their unit. Furthermore, increasing years as a registered nurse improved palliative care knowledge and attitudes.

Conclusion: Nurses who completed the ECEPC had better knowledge of palliative care when compared to nurses who have not undertaken the programme. In addition,

palliative care training should not only focus on drugs and palliative care emergencies but also include a focus on the philosophy underpinning palliative care.

Key words: knowledge, older person, nurses, palliative care.

Introduction

By 2050, estimates indicate that over a quarter of the world's population will be aged 65 years and older. The proportion of people aged over 60 years will double from about 11% to 22% (Horton, 2014), with the greatest percentage increase predicted to be among those aged 85 years and older (Hall et al, 2011). The growth in the older person population has led to the rapid increase in the number of nursing homes and care facilities for older people (Moran, 2009).

Older people with life-limiting illnesses and those nearing the end of their lives have differing and often more complex needs to those in other age groups. Typically, the dying process for an older person is slow, marked by episodes of acute exacerbation followed by recovery. This process leads to a protracted course of gradual decline, disability and eventual death (Kapo et al, 2007). It is this fractured and uncertain timeline that often results in these patients' palliative care needs being overlooked or neglected (Wittenberg-Lyles and Sanchez-Reilly, 2008). Healthcare professionals often delay the introduction of a palliative approach for the older person by waiting for a clearly terminal event. By doing so, the dying patient may have had a poor quality of

life, suffering unnecessarily from preventable symptoms. Early integration of palliative care is being increasingly recommended throughout the literature (Ferris et al, 2009, Gaertner et al, 2012).

The National Institute for Health and Clinical Excellence (NICE) advocates the need for palliative care provision regardless of care setting (NICE, 2004). Palliative care aims to provide comfort to individuals with a life limiting illness (Mc Ilfatrick et al, 2010). There are many definitions and descriptions of palliative care available throughout the literature. For instance, in a discourse analysis of palliative care (Pastrana et al, 2008), a total of 21 English definitions of palliative care were identified from palliative associations and hospice and palliative care services. However, a central theme throughout definitions of palliative care is the promotion of quality of life, with family and multidisciplinary involvement (Goldman et al, 2006).

The definition and philosophy of palliative care has expanded more recently to include life-limiting illnesses which include chronic heart, lung and kidney diseases, neurological disorders and organ failure. As a result of these inclusions, older people are ideally placed to receive a high standard of palliative care. This development has created new challenges, but has also placed new demands on staffing skills within care of the older person settings (Gott et al, 2008). Therefore, it is fundamental that nurses working in care of older people settings have adequate knowledge of palliative care in order to provide quality care to those who may require it (Ronaldson et al, 2008).

Nurses working in older people care settings, such as community hospitals and nursing homes, are ideally placed to deliver palliative care. There is a unique nurse-resident relationship that exists due to long lengths of admission (Frahm et al, 2011) which promotes the delivery of palliative care. Such relationships should enable nurses to monitor changes and broach the subject of palliative care with both residents and families. However, the quality of palliative care delivered to older people is often inadequate (Jerant et al, 2004; Górlén et al, 2013). Moreover, a lack of understanding of the basics of palliative care among nursing home staff has been reported internationally (Ronaldson et al, 2008; McDonnell et al, 2009; Dwyer et al, 2011; Górlén et al, 2013).

The study reported here aimed to determine the palliative care knowledge and attitudes of nurses working in care of the older person settings in one rural region in Ireland and identify palliative care educational needs.

Research Methodology

A cross-sectional methodology was used in this study. Cross-sectional studies use a 'cross-section' of a population and determine a 'snapshot' view. Ethical approval was granted by the ethics committee attached to the main regional hospital in November 2013 to survey all registered nurses (n=97) working in four private and three state run older person care units geographically spread across one rural county in Ireland. The seven care homes represent one third of all older person care centres in the region. The first author met with the manager of each unit, explained the study and left questionnaires in each staff room.

The study instrument consisted of two questionnaires: the Palliative Care Quiz for Nursing (PCQN) (Ross et al, 1996) and the Thanatophobia Scale (TS) (Merrill et al, 1998). The PCQN consists of 20 items that require a 'true', 'false' or 'don't know' response. It is a popular tool that has been used internationally (for instance, Choi et al, 2012; Brazil et al, 2012). The minimum achievable score for the PCQN is zero and the maximum is 20.

The Thanatophobia Scale (TS) (Merrill et al, 1998), designed to assess attitudes to providing palliative care, is a seven-item likert scale and only been used with samples of medical students (Mason and Ellershaw, 2004; Mason and Ellershaw, 2010; Morrison et al, 2012). Scores range from a minimum of seven to a maximum of 49. Greater cumulative scores indicate more negative attitudes towards palliative care and poorer perceived outcomes for patients (Mason and Ellershaw, 2008).

The questionnaire also asked respondents what palliative care training they had undertaken including the European Certificate in Essential Palliative Care (ECEPC). In the region where this study took place, both the local hospice and the Irish Hospice Foundation fund the delivery of the ECEPC. This course is eight weeks in duration and requires two days of attendance at the base from which it is being delivered, one at the introduction night and one on the final day for the exam. The participants are guided on self-directed learning for these eight weeks making it conducive to family and work life. The EPEPC is offered in a number of countries, including Malta and is recognised by the Royal Colleges of Physicians and General Practitioners and by the Universities of Surrey and Ulster.

Completed questionnaires were returned by 61 nurses (response rate 63%). The completed questionnaires were stored in locked cabinet. The questionnaire data was then inputted into a password protected laptop. The inputted data from the returned questionnaires was analysed using IBM SPSS Statistics (Version 20). Descriptive analysis was used to identify totals, mean, standard deviation, median, minimum and maximum figures and identify distribution. Independent Sample T-Test compared the means of various variables containing ordinal and nominal data, and identified the presence or otherwise of significant relationships between these variables. A *p*-value was reported to indicate significance of relationships with a Confidence Interval set at 95%. The significance level was set up at $p < 0.05$. Pearson Correlation was used for data that were evenly distributed, while Spearman's Correlation was used for data that were not evenly distributed. An *r*-value was reported to indicate correlation.

Results

Completed questionnaires were returned by 61 nurses (response rate 63%); 85% (n=52) were staff nurses and 15% (n=9) were nurse managers. No respondent had completed a post-graduate diploma or degree in palliative care (Table 1).

Table 1. Palliative care training in nursing homes and community hospitals

	Nursing Home	Community Hospital
	n (%)	n (%)
European Certificate in Essentials in Palliative Care (ECEPC)	2 (17)	8 (45)
Information session within the unit	7 (58)	4 (22)
Study session outside the unit	3 (25)	6 (33)
Total	12 (100)	18 (100)

The mean score of the PCQN was 11.8 ($\sigma=2.85$) suggesting a moderate level of palliative care knowledge, with the lowest score being 5 and the highest being 18. The highest number of correct responses were achieved for Question 8; *‘Individuals who are taking opioids should follow a bowel regime’* (n=57, 93%). The highest number of incorrect responses was achieved for Question 12; *‘The philosophy of palliative care is compatible with that of aggressive treatment’* (n=56, 92%) (Table 2).

Table 2. Correct and incorrect PCQN responses

		Correct n(%)	Incorrect n(%)
Q 1	Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration (<i>F</i>)	50 (82)	11 (18)
Q 2	Morphine is the standard used to compare the analgesic effect of other opioids (<i>T</i>)	33 (54)	28 (46)
Q 3	The extent of the disease determines the method of pain treatment (<i>F</i>)	20 (33)	41 (67)
Q 4	Adjuvant therapies are important in managing pain (<i>T</i>)	46 (75)	15 (25)
Q 5	It is crucial for family members to remain at the bedside until death occurs (<i>F</i>)	45 (74)	16 (26)
Q 6	During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation (<i>T</i>)	24 (39)	37 (61)
Q 7	Drug addiction is a major problem when morphine is used on a long term basis for the management of pain (<i>F</i>)	33 (54)	28 (46)
Q 8	Individuals who are taking opioids should follow a bowel regime (<i>T</i>)	57 (93)	4 (7)
Q 9	The provision of palliative care requires emotional detachment (<i>F</i>)	45 (74)	16 (26)
Q 10	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea (<i>T</i>)	26 (43)	35 (57)
Q 11	Men generally reconcile their grief more quickly than women (<i>F</i>)	39 (64)	22 (36)
Q 12	The philosophy of palliative care is compatible with that of aggressive treatment (<i>T</i>)	5 (8)	56 (92)
Q 13	The use of placebos is appropriate in the treatment of some types of pain (<i>F</i>)	41 (67)	20 (33)
Q14	In high doses, codeine causes more nausea and vomiting than morphine (<i>T</i>)	26 (43)	35 (57)
Q 15	Suffering and physical pain are synonymous (<i>F</i>)	37 (61)	24 (39)
Q 16	Pethidine is not an effective analgesic in the control of chronic pain (<i>T</i>)	43 (71)	18 (29)
Q 17	The accumulation of losses renders burnout inevitable for those who seek work in palliative care (<i>F</i>)	27 (44)	34 (56)
Q 18	Manifestations of chronic pain are different from those of acute pain (<i>T</i>)	51 (84)	10 (16)
Q 19	The loss of a distant or contentious relationship is easier to resolve than the	36 (59)	25 (41)

	loss of one that is close or intimate (<i>F</i>)		
Q 20	The pain threshold is lowered by anxiety or fatigue (<i>T</i>)	37 (61)	24 (39)

No significant difference was found between the mean PCQN score for staff nurses (11.7/ σ =3.01) and for nurse managers (12.4/ σ =1.59). However, there was a significant ($p<0.0001$) difference (2.9) between the mean PCQN score for nurses working in community hospitals (12.8 / σ =2.39) and in nursing homes (9.9 / σ =2.81).

There was no significant correlation found between age and a higher PCQN score ($p=0.201$). However, the PCQN score improved the longer a nurse was registered. This was found to be significant as Spearman's Correlation showed that $p=0.021$ ($r=0.295$) with a weak to moderate positive correlation.

The mean PCQN score for those who had some form of palliative care education was 12.4 (σ =2.79) and 11.3 (σ =2.85) for those who had no palliative care education. This was found to be not significant ($p=0.141$). ANOVA within the three different types of palliative care education was undertaken (Table 3) showed no significant difference in PCQN scores between those that had an information session within their unit and those who attended a study day outside their unit ($p=0.087$), nor between those who completed the ECEPC and those who had a study day outside their unit ($p=0.762$). However, the mean PCQN score for those who completed the ECEPC was 13.8 (σ =2.39), while the mean score for those who only had an information session within their unit was 10.6 (σ =3.21). This difference in mean scores was found to be significant

($p=0.015$), indicating a higher level of palliative care knowledge in those who had completed the ECEPC.

Table 3 Comparisons within types of palliative care training

		Mean difference	Sig.
Information session within unit	Study day outside unit	2.455	0.087
	ECEPC	3.255	0.015
Study day outside unit	Information session within unit	2.455	0.087
	ECEPC	0.800	0.762
ECEPC	Information session within unit	3.255	0.015
	Study day outside unit	0.800	0.762

The median score of the TS was 14.0 indicating favourable attitudes towards palliative care, with the lowest score being 7 and the highest being 36. The most positive attitudes were seen in Question 3 *'it is frustrating to have to continue talking with relatives of patients who are not going to get better'* (median=1.0) and the most negative attitudes were seen in Question 5 *'It makes me uncomfortable when a dying patient wants to say good bye to me'* (median=2.0) (Table 4).

Table 4. Mean and median scores of each TS question

		Mean	Median
		(SD)	(Min-Max)
Q 1	Dying patients make me feel uneasy	2.23 (1.2)	2.0 (1-6)
Q 2	I feel pretty helpless when I have terminal patients on my ward	2.02 (1.0)	2.0 (1-6)
Q 3	It is frustrating to have to continue talking with relatives of patients who are not going to get better	1.93 (1.3)	1.0 (1-7)
Q 4	Managing dying patients traumatises me	2.46 (1.5)	2.0 (1-7)
Q 5	It makes me uncomfortable when a dying patient wants to say goodbye to me	2.54 (1.5)	2.0 (1-7)
Q 6	I don't look forward to being the personal nurse of a dying patient	1.95 (1.0)	2.0 (1-6)
Q 7	When patients begin to discuss death, I feel uncomfortable	2.10 (1.0)	2.0 (1-5)

No significance was found between the mean TS score for staff nurses (15.2 / σ =5.89) and the mean TS score for nurse managers (15.6 / σ =7.62) (p =0.883). Similarly, no significance was found between the mean TS score for those working in a community hospital was (14.8 / σ =6.68) and for those working in a nursing home (16.1 / σ =4.7) (p =0.407).

However, the TS score was lower the older the nurse was. This was found to be significant as Pearson's Correlation $p=0.006$, and a moderate negative correlation showed that attitudes were more positive as age increased ($p=0.006$, $r= -0.351$) (because a lower TS score reflects more positive attitudes, this results in a negative correlation). The TS score was also found to be lower the longer a participant was registered. This was found to be significant as Spearman's Correlation showed that $p=0.023$, and a weak to moderate negative correlation showed that attitudes were more positive the longer a participant was registered ($p=0.023$, $r= -0.290$) (Table 5) (because a lower TS score reflects more positive attitudes, this results in a negative correlation).

Table 5 Correlation between total TS score and years registered and age

			Years Registered	Age
Spearman's rho	Total TS	Correlation Coefficient	-0.290	-0.351
		p-value	0.023	0.006
		N	61	61
			$p = 0.023$	$p = 0.006$
			$r = -0.290$	$r = -0.351$

The difference in the mean TS score for those who had some form of palliative care education ($14.7 / \sigma=6.36$) and those who had no education ($15.7 / \sigma=5.89$) was not significant ($p=0.523$). A moderate negative correlation was also found between the total PCQN scores and the total TS scores. As the total PCQN scores increased the total TS scores decreased showing that a higher level of palliative care knowledge correlates to more positive attitudes towards palliative care. This was found to be significant as Pearson Correlation showed that $p=0.007$ ($r= -0.340$).

Discussion

A higher percentage of participants working in nursing homes ($n=12$, 60%) had palliative care training when compared to those working in community hospitals ($n=18$, 44%). A greater number of participants working in community hospitals had completed the ECEPC and undertaken study days outside the unit. Those who had completed the ECEPC had significantly higher PCQN scores than those who had had an information session within their unit. This suggests that of the three types of palliative care education available to the study respondents, higher levels of palliative care knowledge were found in those who had completed the ECEPC.

The mean score of the PCQN was 11.8 ($\sigma=2.9$) and is similar to an Australian study involving nurses ($n=97$) in an aged-care facility where the mean PCQN score was 11.7 ($\sigma=3.1$) (Ronaldson et al, 2008). However, the correct scores in our study ranged from 25-90% which suggests a high degree of variability in palliative care knowledge among the nurses sampled.

The highest number of correct responses on the PCQN was for Question 8; 'Individuals who are taking opioids should follow a bowel regime' (n=57, 93%). This question was also the most correctly answered in Brazil et al.'s (2012) study. This finding was not surprising as constipation is an extremely common side-effect of opioids and stringent bowel care is a fundamental expectation in palliative care (Leppert, 2014). The highest number of incorrect responses were achieved for Question 12; 'The philosophy of palliative care is compatible with that of aggressive treatment (n=56, 92%). This question was also the most incorrectly answered in other studies with nurses in long-term care settings that have utilised the PCQN tool (Ronaldson et al., 2008; Brazil et al., 2012). This suggests the need to include a focus on the philosophy of palliative care in any educational programme because a philosophy of palliative care not only focuses on symptom management and relief of suffering but also the promotion of quality of life. This expansion of palliative care philosophy illustrates its blurred boundaries with end-of-life care, which although is an important part of palliative care, also refers to the care of a person during the final part of their life journey, from the point at which it is clear that the person is in a progressive state of decline (Watson 2005). This latter point is significant. 'Generalists' continue to express difficulties in defining 'palliative care' and refer to it as a specialist palliative service, rather than 'a philosophy and practice of care' that is an essential part of the care they deliver (Gott et al 2011, p.235). Furthermore, understanding of 'end-of-life' is reported as poor among health care professionals. Most participants in Gott et al's (2011) study defined end-of-life in terms of days and weeks before death and not as defined as the Department of Health (2008), as the last 12 months. Understanding of end-of-life is especially relevant in older person care where

the need for end-of-life care is often at a time quite distant from their death and end-of-life care for older people is not dependent on knowing when someone is going to die (Froggatt & Payne 2006).

A focus on palliative care philosophy would also need to address the role of advanced care directives. Advance care planning has become a standard for person centred care at end of life (McCarthy et al 2010). In the context of older people in long stay care, this can include an advance statement of a resident's wishes and preferences or an advance decision to refuse treatment in a predefined future situation.

A statistically significant correlation between PCQN score and years registered was found, showing that nurses' knowledge improved the longer they were registered.

On the Thanatophobia Scale, results became more favourable the older a nurse was and the longer a nurse was registered, indicating more positive attitudes towards palliative care and dying as age and experience increased. It is argued that nurses' attitudes towards death and dying are positively affected by experience (Mutto et al, 2010). In terms of practice, this finding suggests that younger, less experienced nurses would benefit from working alongside older, more experienced nurses. Moreover, in terms of education, younger, less experienced nurses may benefit from exploration of their attitudes to palliative care and dying as part of any palliative care training programme.

The most negative attitudes were seen in Question 5 on the TS; 'It makes me uncomfortable when a dying patient wants to say goodbye to me'. Discussing death and dying has been described 'difficult' (Fields et al, 2013; Whellan et al, 2014). This finding suggests that a focus on drugs and palliative care emergencies training for nurses working in non-specialist units is not enough, and must also include discussions on the philosophy underpinning palliative care as highlighted earlier.

There was a moderate negative correlation between the total TS score and the total PCQN score, meaning that as the palliative care knowledge level increased, the palliative care attitudes became more positive. This link between knowledge and attitudes has also been reported elsewhere, with studies showing a positive relationship between good palliative care knowledge and positive attitudes towards caring for those who have a terminal illness (Thulesius et al, 2002; Vejlgaard and Addington-Hall, 2005; Ho et al, 2010).

Limitations

The sample size of nurses (n=61) is relatively small and from a rural setting only, however, the sample size compares well to Brazil et al.'s (2012) recent Canadian study of 69 nurses. Moreover, data was collected at one point in time and different results may have been found if data was collected over different time periods. It can be difficult therefore to make casual inference in cross-sectional studies (Levin 2006).

Conclusion

The study results indicate moderate knowledge and positive attitudes of palliative care among nurses working in older persons' care settings. Although palliative care training did not impact on the mean overall scores in this study, there was a significant difference in the PCQN scores of those who had completed the ECEPC compared with those who had information sessions within their unit. All nurses working in care older people settings should be supported to undertake the ECEPC. Finally, younger, less experienced nurses would benefit from working alongside older, more experienced nurses when delivering palliative care in older people care settings.

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