

**Quantitative Study of the  
Attitude, Knowledge and  
Experience of Staff Nurses on  
Prioritizing Comfort Measures  
in Care of the Dying Patient in  
an Acute Hospital Setting**

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## **Abstract**

### **Background:**

When the prognosis for a patient is imminent death, hospice care concentrates on the quality of life of the patient, reducing the severity of the disease symptoms rather than vainly trying to treat the disease itself. To assist in delivery of this type of quality end-of-life care to patients in acute hospitals the Irish Hospital Foundation (IHF) developed a Hospice Friendly Hospital programme (HFH). This HFH developed the Quality Standards for End-of-Life Care in Hospitals to set out a shared vision for the type of end-of life care that each hospital should aim to provide. This development is significant as almost 50% of those who die in Ireland die in hospital and care of the dying in Irish hospitals, while regarded as good, is described as 'care at the end of life' rather than 'end-of-life care' because the care seems to lack an effective palliative care component" (McKeown *et al.* 2010, p.158).

### **Literature Review**

To investigate international perspectives on end-of-life care, the current international literature was reviewed using the key themes of identifying the dying phase, comfort care and symptom control for the dying patient. It was concluded from the literature review that nurses and medical staff often differed in their approach to care of the dying patient and this hindered effective delivery of end-of-life care. Education on end-of-life care was recommended in the literature as being a solution to the problems in delivering this care even though research had not been done on the status quo in education.

### **Research Problem**

It would seem necessary to first investigate the education and training levels of nurses and doctors in end-of-life care and to investigate if attitudes and experience also influence the medical and nursing models in the delivery of this care. This research proposal is concerned only with the nursing perspective on end-of-life care and the research question is: "What are the attitude, knowledge and experience of nurses on prioritizing comfort measures for dying patients in an acute hospital?"

### **Methodology**

A quantitative approach using a descriptive design is proposed for this study. Questionnaires will be used as the data collection method with a simple random sample of 200 staff nurses employed in a Dublin hospital being selected as participants in the study.

### **Proposed outcome of the study**

It is hoped that the results of the study will ascertain nurses' attitude, knowledge and experience in the domain of comfort care of the dying in Ireland and indicate what interventions are needed through education, training and management. It is hoped that the research findings will also highlight the necessity for planning on-going education and training for nurses in care of the dying.

# Chapter 1

## 1.1. Introduction

I propose to study the attitude, knowledge and experiences of nurses on prioritizing comfort measures in care of the dying patient in an acute hospital setting. I am particularly interested in this field as I worked in a hospice where palliative care of the dying concentrated on the quality of life of the patient. When the prognosis for the patient was imminent death, care was focused on reducing the severity of the disease symptoms rather than vainly trying to stop or delay development of the disease itself or provide a cure.

To assist in the delivery of similar quality end-of-life care to patients in acute hospitals, the Irish Hospital Foundation (IHF) developed the Hospice Friendly Hospital programme that respects the curative model of care but ensures that the quality of life of the dying patient is valued (IHF 2010). This programme developed the Quality Standards for End-of-Life Care in Hospitals in consultation with hospital staff, professional bodies and others to set out a vision for the type of end-of life care that each hospital should aim to provide.

In an audit conducted on the care-of the dying McKeown K. *et al.* (2010) noted that the development of standards for end-of-life care was important as almost 50% of those who die in Ireland die in hospital and this trend looks set to increase, for a variety of reasons. In the audit the researchers draw the conclusion that care of the dying in Irish hospitals is good but that it “tends to be generic rather than specific in the sense that it might be more appropriate to describe it as ‘care at the end of life’ rather than ‘end-of-life care’, because the care seems to lack an effective palliative care component” (McKeown K. *et al.* 2010, p.158).

To investigate the current international perspectives on end-of-life care and its delivery a review of recent literature on the topic was conducted.

## 1.2. Literature Review (See appendix I for details of search)

The literature review identified three key themes in end-of-life care:

- (i) Identification of the Dying Phase
- (ii) Comfort Care

(iii) Symptom Control

McKeown K. *et al.* (2010) stated that when patients have been diagnosed as dying, their care goals should be adjusted to comfort care and symptom control. Research studies on the care of the dying patient were reviewed under the above headings to investigate the approaches to the delivery of this care.

### **1.3. Identification of the Dying Phase**

Failure to recognise that a patient is dying affects the quality of end-of-life care they receive (Thompson *et al.* 2006). The following recent research articles discuss identification of the dying phase (Dalgaard *et al.* 2010, McKeown A. *et al.* 2010, Walker & Read *et al.* 2010 and Willard & Luker 2010).

In a qualitative study of terminal illness stages, Dalgaard *et al.* (2010) found that it was important to note the late palliative phase as a progression towards death. The research approach was one of observing various staff functions and conducting informal interviews with patients (n=74), relatives (n=11), doctors and nurses in a haematology department in an acute hospital in Denmark. The unpredictability of haematological malignancies, patients' and relatives' lack of acceptance of impending death and their investment of hope in further treatment, were found to hinder doctors in formally identifying the dying patient. Nurses reported poor inter-professional cooperation, caused by doctors focusing on treatment and cure, while nurses gave priority to the patient's general condition. Dalgaard *et al.* concluded that open communication with all concerned in decision making was essential in the transition to the terminal phase. The study is limited to one hospital and the findings cannot be generalized.

The qualitative study on the delivery of palliative care in an intensive care unit (ICU) in Scotland conducted by McKeown A. *et al.* (2010) also examined the difficulty of identifying the dying phase, using a grounded theory interview-based approach. The volunteer sample was comprised of 10 nurses, 5 consultants and 10 junior medical staff. Nurses reported that dying patients were treated aggressively for too long with a focus on cure instead of palliative care. Doctors stated that they were responsible for deciding when to cease curative care and begin palliative care but many preferred to wait for obvious signs that the patient had deteriorated rather than intervene. Nurses felt they had a more accurate view

of their patients' conditions but they found it difficult to get the doctors to accept this. McKeown A. *et al.* suggested that multidisciplinary team education on palliative care would improve confidence in decision-making in end-of-life care issues. While it is recommended in this study that education on end-of-life care is needed there is no actual assessment of this.

A qualitative study conducted by Walker & Read (2010) on care of the dying in an ICU in England using the Liverpool Care Pathway (LCP) had similar findings on identification of the dying phase. The LCP is commenced on the presence of two out of the following four criteria: "the patient is bed bound, semi-comatose, only able to take sips of fluid or no longer able to take tablets" (Kinder & Ellershaw 2003, p.12). The LCP is an inter-professional documented care pathway that provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medication and discontinuation of inappropriate interventions (Jack *et al.* 2003). The LCP provides frequently monitored outcomes of care in the last days of the patient's life (see Appendix II). A purposive convenience sample of doctors (n=1) and nurses (n=5) who had used the Liverpool Care Pathway (LCP) was interviewed in a descriptive phenomenology study. It was considered that when end-of-life decisions were made the doctor actually made the decision and care of the patient was then handed over to nurses. Some nurses felt that the weight of responsibility made end-of-life decision-making difficult for doctors. Nurse felt their own education was adequate, but doctors and nurses both felt that education in this field was lacking for doctors. As in the previous study Walker & Read concluded that there was need for interdisciplinary educational strategies on end-of-life care in the ICU. However doctors' and nurses' education on end-of-life care had not been specifically researched.

Similarly, Willard & Luker (2010) conducted a qualitative study using a grounded theory approach, to study factors that hinder end-of-life care in the acute hospital setting in England. The participants were cancer nurse specialists (n=29) selected through purposive sampling to include valuable informants. Nurses reported that the critical point when a dying patient's treatment should be re-evaluated was not always recognised because palliative care was viewed as 'giving up' on the patient. The challenges of diagnosing dying and the existence of treatments

available to sustain life were proposed as explanations for end-of-life decisions being difficult. Nurses stated they were frustrated when cancer patients died undergoing active treatments and routine practice took precedence over a patient's comfort. Again, Willard & Luker state the need for professional consensus that the patient is dying to ensure that appropriate end-of-life care is initiated. The study findings clearly show that this is the case.

#### **1.4. Comfort Care**

In a guide to implementation of the LCP Preston (2007) promoted the use of comfort care and the reduction of unnecessary routine nursing interventions such as vital signs measurement and unnecessary movement of the patient in the final days of life. The following recent research articles discuss comfort care for the dying patient (Jack *et al.* 2003, Thompson *et al.* 2008, van der Riet *et al.* 2008 and Espinosa *et al.* 2010).

Jack *et al.* (2003) conducted a qualitative study of nurses' perceptions of the Liverpool Care Pathway in the acute hospital setting in England. A purposive sample (n=15) of network nurses took part in focus group interviews. Following training in care of the dying, network nurses are leaders in delivering palliative care on their ward. Participants reported that prior to the introduction of the LCP vital signs measurements had been performed as a matter of routine even though this disturbed the patients unnecessarily and the results of the observations were not acted upon. This regular routine care of dying patients had been discontinued when the LCP had commenced. Nurses also reported that the LCP advanced their knowledge on what care was necessary and boosted their confidence in caring for the dying patient. This study was conducted in the hospital where the LCP had been developed. Nurses had undergone education and training in end-of-life care and this was seen as a factor in the successful delivery of comfort care. Jack *et al.* (2003) concluded that wider research on the topic with a larger sample is necessary.

A less satisfactory experience on delivery of comfort care was found by Thompson *et al.* (2008) in a qualitative study using a grounded theory approach to examine the transition of care from curative to palliative. Semi-structured interviews were conducted on a convenience sample of nurses (n=10) from two Canadian

hospitals. Nurses perceived that physicians hesitated switching to end-of-life care measures because they viewed commencing palliative care as doing nothing for the patient. Nursing staff were frustrated that the over-emphasis on the curative model impacted on their ability to deliver comfort care as they were required to perform redundant procedures rather than care holistically for the patient. Thompson *et al.* concluded from the research evidence that it is essential that all parties acknowledge the fact that cure of the disease is not possible before establishment of an appropriate end-of-life care plan based on the patient's needs. They also recommend further research be conducted on reducing the barriers to changing care from curative to palliative in medical units.

Similar barriers to delivering optimal terminal care were found in a qualitative study conducted by Espinosa *et al.* (2010) in the USA on ICU nurses' experiences. A descriptive phenomenological study using a purposive sample of ICU nurses (n=18) was conducted by holding focus group interviews on previously identified themes. As in the study conducted by Thompson *et al.* (2010) it was found that nurses considered that the different perspectives in medical and nursing care presented a problem for their delivery of comfort care to the dying patient. Nurses who were trying to achieve a peaceful end-of-life for the patients found it difficult to deliver care ordered by physicians when it had no apparent benefit to the patient. Relatives' unrealistic expectations that everything possible be done for the patient, was also a barrier to delivery of end-of-life care. Based on the study it was concluded that nurses needed education and training on delivering terminal care and that education by observation was not sufficient. Espinosa *et al.* also recommended that research be conducted on methods to improve communication between the different professionals involved in end-of-life care.

Evidence of polarization between palliative care and acute care was found in a qualitative study conducted in Australia by van der Riet *et al.* (2008) on nutrition and hydration at the end of life. Data was collected through focus group meetings with nurses (n=15), some working in a tertiary referral unit and others working in an acute hospital ward. Separate interviews were held with four doctors from the units. It was found that nurses and doctors following the palliative care ethos viewed medically assisted hydration and nutrition as invasive for the dying patient and their approach was to promote comfort and quality of life. However, in the

acute care setting, care for the dying patient involved use of medical provision of fluids. Palliative care professionals felt that a dry mouth for a dying patient did not indicate thirst and that good mouth care was more appropriate than medical hydration. Food was offered to dying patients but often they were not hungry as hormones could shut off their appetite. These issues were found to be of great concern to carers and could influence decisions on care. The focus group approach limited open discussion but there was consistency in the ideas discussed. The researchers recommended that larger studies be conducted on the topic in both palliative and acute settings. They also recommended that education on managing terminal hydration was necessary for healthcare professionals and that carers should also be educated on this matter.

### **1.5. Symptom Control**

Comfort care of the dying includes advance planning for symptom control (Preston 2007). Pain, nausea, vomiting, agitation and respiratory tract secretions are among the most usual symptoms in the dying patient (Glare *et al.* 2003). The following recent research articles discuss controlling symptoms for the dying patient (Toscani *et al.* 2005, Gambles *et al.* 2006, Watson *et al.* 2006 and Lhussier *et al.* 2007).

Toscani *et al.* (2005) conducted a quantitative study on how people die in hospitals by collecting data from clinical records and interviewing the nurses in charge of dying patients (n=370) in 40 hospitals in Italy. They found that a substantial proportion of dying patients received inadequate symptom control (75%) and inadequate pain relief (40%). Dying patients also suffered distressing symptoms such as nausea, vomiting, insomnia and anorexia. It was found that nurses assessed the overall management of the patient as good/excellent in 88% of cases despite the presence of uncontrolled symptoms. Toscani *et al.* considered that pain and symptom control was poor in these hospitals and resources should be provided to improve end-of-life care and educate health care professionals. The conclusion that end-of-life care needs to improve is valid but the education level of the healthcare professionals had not been researched in the study. The study had a small sample size, only involved large/medium hospitals and did not distinguish between medical and surgical wards where the culture of terminal care could differ.

Gambles *et al.* (2006) conducted a qualitative survey of doctors' and nurses' perceptions of the LCP in hospices in the U.K. using exploratory interviews. The purposive sample was comprised of nurses (n=8) and doctors (n=3). Doctors felt that patients had better symptom control with the use of the LCP, as symptoms were picked up and addressed earlier. They felt that good care and symptom control contributed to a good death. Nurses reported that the LCP made it clear to inexperienced staff what they could expect when looking after a dying patient. They also felt that the use of the LCP made them more pro-active and consistent in management of issues for the dying patient. Gambles *et al.* recommended that continued education was necessary with the use of the LCP. The fact that the LCP had been developed in the hospice where the study was conducted introduced a bias into the findings so they could not be generalised.

With a view to developing good quality end-of-life care the LCP was introduced in a volunteer sample of nursing homes (n=8) in the U.K. by Watson *et al.* (2006) over a twelve month period, using an action research approach involving field notes and questionnaires. It was found that there was a lack of control of end-of-life symptoms due to poor knowledge of palliative care drugs among staff. From patient notes it was found that loss of swallowing reflex was seldom noted for dying patients and as a result subcutaneous or rectal medication were rarely prescribed to circumvent the problem. Watson *et al.* viewed anticipatory prescribing of the necessary drugs for symptoms that might arise as being necessary in end-of-life care. They also concluded from their research that collaborative learning groups are useful for sustaining change in practice in end-of-life care. The findings on symptom management are relevant to all care settings.

Similarly Lhussier *et al.* (2007) conducted a quantitative evaluation using action research methodology in two Primary Care Trusts in England with a view to introducing an end-of-life integrated care pathway (ICP) for the dying. The volunteer sample of participants was comprised of ICP facilitators (n=10), professionals implementing the ICP (n=22) and bereaved carers (n=10). Professionals felt that the ICP enabled them to pin point symptom problems and address them before they became too serious for the patient. One respondent commented that the ICP made staff more pro-active in checking on symptoms. Some criticism of the LCP model of care was expressed as it was felt that its 'tick-

box' approach resulted moved the focus from the symptom control and comfort care needed by the dying patient. However Lhussier *et al.* (2007) concluded that overall the implementation of the ICP had met several challenges in end-of-life care. They considered that palliative care should be given a higher profile on the professional agenda.

## **1.6. Conclusion**

The research articles reveal some disagreement between nurses and doctors about when patients enter the dying phase. Many studies show the need for professional consensus that the patient is dying before appropriate end-of-life care can be initiated. Some studies found that even when the patient was identified as dying doctors continued with diagnostic and therapeutic interventions and this frustrated nurses who wished to deliver care focused on comfort and symptom control.

Studies on the use of the LCP found that training contributed to the successful delivery of comfort care for the dying. Even though the health care professionals' education level in end-of-life care had not been noted in most of the other studies it was recommended in many of the reports that provision of education on end-of-life care was necessary.

## **1.7. Research Problem**

Before planning such specific education programmes, it would seem necessary to conduct research studies to establish the education and training levels of nurses and doctors in end-of-life care and to establish if attitudes and experience also influence the medical and nursing models in the delivery of this care. This research proposal is concerned with the nursing model and it proposes to establish what influences the nurse's approach in delivering end-of-life care.

## **1.8. Research Question**

The research problem leads to the following research question:

“What are the attitude, knowledge and experience of nurses on prioritizing comfort measures for dying patients in an acute hospital?”

## **1.9 Objectives**

- (i) To establish the attitude of nurses on prioritizing comfort measures for dying patients.
- (ii) To establish if nurses' knowledge of prioritizing comfort measures for dying patients is adequate.
- (iii) To establish if nurses' experience in prioritizing comfort measures for dying patients is significant.

## **Chapter 2: Methodology**

### **2.1 Introduction to Research Methodology**

The methodology selected for the proposed study will be detailed here. The planned research design, methods of sample selection, data collection and analysis of results will be explained. Ethical considerations for this particular research study will also be detailed. It is hoped that the chosen methodology will generate useful information through the collection and analysis of data on the attitude, knowledge and experiences of staff nurses on the effect of comfort measures in care of the dying patient in the acute hospital setting.

### **2.2 Research Design**

The research design of a study outlines the basic approach that researchers use to answer their research question (Polit & Beck 2010). To meet the aims and objectives of the study it is important that the researcher selects the most appropriate design for achieving the aims of the study (Parahoo 2006).

The quantitative approach arises from the belief that human phenomena and variables in human behaviour can be studied objectively (Parahoo 2006) and so this approach has been chosen as an appropriate research method. Quantitative research uses a fixed design that organises in advance the research question and a detailed method of data collection and analysis (Robson 2007). A descriptive design involving a survey, as outlined by LoBiondo-Wood & Haber (2006), is chosen for this study. It is proposed that this survey will collect details of the current attitude, knowledge and experience of nurses on comfort care of the dying patient. The method of data collection chosen is a written questionnaire, allowing large sample size without major expense, to produce quantitative data that can be analysed by statistical computer programmes,

### **2.3 Population/sample**

Parahoo (2006, p. 258) defines a population as “the total number of units from which data can potentially be collected”. The population in this study will be staff nurses working in the acute hospital setting in Ireland. This population will be delimited to a homogenous group of subjects through inclusion/exclusion criteria.

The resultant group will form the target group, the set of nurses about which the researcher proposes to make generalisations (Haber 2010).

#### **Inclusion criteria**

- Registered general staff nurses who work in the acute-care setting.

#### **Exclusion criteria**

- Staff nurses working with children
- Agency staff nurses

Staff nurses, fitting the above criteria, from a large Dublin acute hospital will be chosen as a smaller convenience group of the target population. It is then proposed to select a simple random probability sample (from the convenience sample). Proctor *et al.* (2010) maintain that the use of probability sampling in quantitative research reduces errors and biases in the study. Sampling is the process by which researchers select a proportion of the target population, as the study population, to represent the entire unit. It is more practical and economical to work with samples rather than with large target populations (Polit & Beck 2010). The researcher will obtain the names of all eligible nurses from the Human Resources Department in the hospital. This list of nurses will form a sample frame from which the researcher will select nurses at random by assigning a number to each name and 'picking the numbers out of a hat' (Proctor *et al.* 2010).

#### **Sample size**

In quantitative research the size of the sample should be calculated at the design stage (Proctor *et al.* 2010). According to Polit & Beck (2010) quantitative researchers should select the largest sample possible so that it is representative of the target population. For this reason it is proposed to use a sample size of 200 nurses for the study but expert advice on sample size will be sought from a statistician at the design stage. According to Parahoo (2006) the study sample can lose some subjects through non-participation resulting in the achieved sample. The lower the response rate in data collection the less representative the data becomes. Researchers need to explain a low response rate as it may cause bias in the data collected. As Parahoo (2006) recommends the response rate will be compared with the norm in similar studies to ensure an acceptable sample size.

## **2.4 Data collection**

Quantitative data are collected to classify and describe attributes, behaviours and activities of populations according to Parahoo (2006). Data collection should be objective, systematic and repeatable (Lacey 2010). Robson (2007) maintains that a researcher should use the simplest manner of collecting the data to get answers to the research question and should not collect any more data than necessary. Mindful of these conditions the data collection instrument selected for this study is a questionnaire.

### **Questionnaires**

A questionnaire is a method of data collection that asks participants to give written or verbal replies to a written set of questions (Parahoo 2006). It is a quick, convenient and inexpensive method of collecting standardised information (Jones & Rattray 2010). A questionnaire can be used to collect information on attitudes, knowledge and experience of staff (Parahoo 2006). A structured written questionnaire that uses a quantitative self-report technique, as outlined by Polit & Beck (2010), will be used to collect data in this study.

The questionnaire will have three parts (see Appendix III). Part A of the questionnaire will use a Likert-type scale to gather data on the attitudes of nurses on the effect of comfort in care of the dying. According to Parahoo (2006) a Likert-type questionnaire formulates statements which the researcher considers will represent the concept being measured without going through the validation process used in a Likert scale. The questionnaire will consist of positively and negatively worded statements with six different response options ranging from strongly disagree to strongly agree. Positive statements are scored one to six (one for strongly agree through to six for strongly disagree) and scores are reversed for negative statements. The score for each item will be reported individually. Parts B and C will use a fill the box format and will gather data on the knowledge and experience of nurses on comfort care of the dying respectively.

Questionnaires tend to have a low return rate (Parahoo 2006). In an attempt to overcome this problem the researcher will take the following steps:

- (i) A cover letter (see Appendix IV) will be sent with the questionnaire explaining the aim of the research study and guaranteeing confidentiality of the responses. A reminder letter will be sent to respondents three weeks after the initial contact.
- (ii) According to Parahoo (2006) 'respondent burden' puts a pressure on respondents through the time and effort necessary to complete a questionnaire. To reduce this burden closed-ended questions which are more efficient and less time consuming for respondents will be used and instructions will be clear (Polit & Beck 2010).

## **2.5 Validity and reliability**

### **(i) Validity**

Polit & Beck (2010) define the validity of a questionnaire as the degree to which the instrument measures what it is intended to measure. The questionnaire should adequately address all aspects of the issues being studied. Face validity and content validity are the validity issues most frequently reported in the literature (Parahoo 2006).

Face validity basically checks that the questionnaire seems to measure the concept being tested (LoBiondo-Wood & Haber 2010) and this will be assessed by getting friends to test-run the instrument to see if the questions appear to be relevant, clear and unambiguous as outlined by Jones & Rattray (2010).

A content validity test checks that there are enough relevant questions covering all aspects being studied and that irrelevant questions are not asked (Parahoo 2006). The test is based on judgement as no objective methods exist. A panel of experts is used to evaluate the content validity of new questionnaires (Polit & Beck 2010). The questionnaire will be submitted to such a panel to check that the questions reflect the concepts being studied and that the scope of the questions is adequate, in the manner proposed by LoBiondo-Wood & Haber (2010). The judges will include course lecturers in Research and Palliative Care and nurses qualified in Palliative care with research experience on the topic.

## **(ii) Reliability**

According to Parahoo (2006) reliability is a necessary but not sufficient condition for validity. Reliability of a questionnaire refers to its ability to yield the same data when it is re-administered under the same conditions but it is difficult to obtain a replication of data when you are dealing with people (Robson 2007). Reliability refers to accuracy of measurement. Reliability for quantitative research focuses mainly on stability and consistency (Polit and Beck 2010).

The stability of a questionnaire is the degree to which it produces similar results on being administered twice. As recommended by Polit and Beck (2010) the researcher proposes doing a stability test using the test-retest method on a small population. The questionnaire will be administered on two occasions, two weeks apart and the results compared. A reliability coefficient will be calculated on the two sets of data for each part of the questionnaire. Reliability coefficients range from 0.00 to 1.00, with higher values indicating greater reliability. According to Jones & Rattray (2010) good reliability is indicated by a coefficient  $> 0.8$ , so the researcher will attempt to achieve a reliability of this level or greater. The 'test-retest' will be included in the pilot study.

Whether or not questions measure the same concept is checked by an internal consistency check (Jones & Rattray 2010). The researcher will use the split-half test described by Parahoo (2010) to check internal consistency. The questionnaire will be split into two equal halves and the data will be checked for similarity. Consistency will be checked by Cronbach's alpha as described by Polit and Beck (2010). Cronbach's alpha has a range of values between 0.00 and 1.00 and a value of  $> 0.7$  is acceptable.

## **2.6 Data analysis**

According to Parahoo (2006, p.375), data analysis is "an integrated part of the research design", and it is a means of making sense of data before presenting them in an understandable manner. Descriptive analysis will be carried out on the data collected. Analysis of quantitative data is carried out using numbers so the

reply to each question of Part A of the questionnaire will be coded using numbers on an ordinal scale of 1 to 6. Numbers on an ordinal scale are in ascending order, with no equal steps implied between the numbers (Parahoo 2006). The reply to each question of Parts B and C of the questionnaire will be coded using numbers in the normal sense. The services of a statistician will be engaged to input the data directly to the computer package SPSS (Social Packages for the Social Sciences) and to analyse the data as advised by Walters & Freeman (2010). The computer package will describe the data using frequency and central tendency, as outlined in Parahoo (2006). The frequency of a particular response to a question will be calculated as a percentage and the data will be illustrated using tables and bar charts. Tables facilitate presentation of large amounts of data and bar charts give a clear picture of results with a sense of proportion (Parahoo 2006). Central tendency of the data will be calculated using the mode (most frequent response) for Part A as the data are represented by ordinal numbers. For Part B and Part C central tendency will be calculated by calculating the mean response and the normal distribution around the mean. As advised by Cormack (1991) the researcher will check on the format and relevance of the charts and tables produced by computer analysis.

To check on possible connections between variables inferential statistics are used (Parahoo 2006). Correlations will be checked between (i) data on participants' number of years nursing and the data in Part A of the questionnaire and (ii) participant's education in end-of-life care and data in Part A of the questionnaire. Contingency tables (as described by Polit & Beck 2010) will be set up to cross-tabulate the above variables. Correlation coefficients will be calculated to check the intensity and direction of the correlations. The values of these coefficients can range from + 1.00 for a positive relationship through 0.00 to - 1.00 for a negative relationship (Polit & Beck 2010).

Back-up of computer records will be requested throughout the analysis process. The data will also be stored on a computer made secure by passwords. The completed questionnaires will be kept in a secure place as this is vital both for back-up and security reasons.

## **2.8 Pilot study**

Piloting is a key stage in the development of the questionnaire allowing evaluation of the instrument before the main study is conducted (Parahoo 2006). The pilot study is conducted on a small sample of the population in the same manner as the main study. It gives the researcher the opportunity of checking if the respondents understand the questions in the same way, if all questions are relevant and if all the instructions are clear. The pilot study also allows a check on whether the length and structure of the questionnaire are problematic (Parahoo 2006). The validity and reliability of the questionnaire can also be checked at the pilot study stage (Jones & Rattray 2010).

A pilot study will be carried out using a small sample of subjects, 10% of the main study (T.C.D. Guidelines 2010). Twenty subjects will be chosen in the same manner as the subjects for the main study. The pilot participants will be debriefed to check for problems with the questionnaire and issues concerning it. The structure and content of the questionnaire will be amended accordingly.

As recommended by Robson (2007) the researcher will use the data collected in the pilot study to generate dummy data for 200 participants in order to run a trial test on the selected method of data analysis. Care will be taken that the participants in the pilot study will be excluded from the main study and that details of the study are not passed on to main study participants.

## **2.9 Ethical considerations**

According to Polit and Beck (2010), researchers must deal with ethical issues when their intended research involves human beings. Ethical approval will be requested in writing from the Director of Nursing (as gatekeeper) and the Hospital Ethics Committee of the hospital involved in the research (See Appendices V and VI). As gatekeeper, the director of Nursing must be made aware of all nursing research taking place in the organisation to monitor the effect of all such projects taking place. She will also need to be convinced of the value of the research and the competency of the researcher (Lee 2005).

The main ethical principles that will be considered in conducting this research study are respect for persons, confidentiality and beneficence /non-maleficence.

### **Respect for persons**

As individuals are autonomous beings they have the right to decide whether or not they get involved in this research. This fact will be stated clearly in the questionnaire cover letter (See appendix IV). Informed consent should be sought from research participants (Parahoo 2006). Before consent is sought the researcher will give details of the nature and purpose of the research, the potential subjects, who will have access to the data and the proposed outcome of the research. Completion of the questionnaire by participants will be taken as their giving consent to participate in the study. Participants will be given adequate time to consider their participation.

### **Confidentiality**

Self-administered questionnaires can potentially protect the anonymity and privacy of the respondents contributing to the confidentiality of the responses. To ensure that confidentiality is truly protected the questionnaires will not be numbered.

### **Beneficence/non-maleficence**

While questionnaires are considered to be less intrusive than interviews, observations or experiments they can still potentially cause harm (Parahoo 2006). It is possible for sensitive and highly personal questions to be threatening if they trigger traumatic memories or guilt when the respondent is alone and without support. At the pilot study stage the questionnaire will be checked for potentially damaging questions. Parahoo (2006) maintains that questions on knowledge, behaviour or experience may also be threatening to health professionals if data can be accessed by their employers. A written guarantee will be given to the participants that the data collected will remain confidential and that only the researcher and the statistician employed by the researcher will have access to it.

## **Chapter 3: Proposed Outcome of Study**

### **3.1 Proposed Outcome**

Following this proposed study, a report will be compiled discussing all aspects of the research process including the results, limitations and benefits. It is anticipated that the results of the study will give an indication of nurses' attitude, knowledge and experience in the domain of comfort care of the dying in Ireland and indicate where interventions are needed through education, training or management. It is also anticipated that the findings of the research study will reveal if other factors such as attitude or experience impact on the effective delivery of care of the dying patient.

It is anticipated that these results will contribute to recommendations in future nursing practice, nurse education and research and that this will in turn move palliative care higher up on the agenda of the nursing profession in general.

This study will have limitations as it will be conducted in only one acute hospital. It will give a general overview of the current attitude, knowledge and experience of nurses in this hospital. The researcher recommends that other studies, both quantitative and qualitative be carried out in hospitals in other Irish cities so that a more general picture could be established of end-of-life nursing care in acute hospitals in Ireland. Qualitative research is explanatory and descriptive in nature and so it could help in determining the nature of the phenomena being studied (Barroso, 2010) and consequently give a more complete picture of care of the dying.

It is the intention of the researcher to share the findings of the study with management of the partaking hospital and the schools of nursing and midwifery in Ireland. It is hoped that this will highlight the necessity of planning on-going education and training for nurses in end-of-life care.

To present the research report to a broader audience the researcher intends applying for publication of the study report in relevant nursing journals.

### **3.2 Time Scale**

A clear and practical time scale is necessary to facilitate the organisation and coordination of each stage of the research process and the successful integration of the stages (Cormack, 1991). An 18 month period is proposed as the time frame for this study and a detailed integrated time plan is included in appendix VII.

### **33. Resources**

An estimated budget account for the proposed study is outlined in appendix VIII.

## Reference List

- Barroso J. (2010) Introduction to Qualitative Research. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice* 7<sup>th</sup> edn. (Lobiondo-Wood G. & Haber J., eds), Mosby Elsevier St. Louis.
- Cormack D.F.S. (1991) *The Research Process in Nursing*, 2<sup>nd</sup> edn. Blackwell Scientific Publications, Oxford.
- Dalgaard K., Thorsell G. & Delmar C. (2010) Identifying transitions in terminal illnesses trajectories: a critical factor in hospital-based palliative care. *International Journal of Palliative Nursing* **16** (2), 87 – 92.
- Espinosa L., Young A., Symes L., Haile B. & Walsh T. (2010) ICU nurses' experiences in providing terminal care. *Critical Care Nursing Quarterly* **33** (3), 273 - 281
- Gambles M, Stirzaker S, Jack B & Ellershaw JE (2006) The Liverpool Care Pathway in hospices: an exploratory study of doctor and nurse perceptions. *International Journal of Palliative Nursing* **12**(9), 414 – 421
- Glare P., Dickman A. & Goodman M. (2003) Symptom control in care of the dying. In *Care of the Dying: A pathway to excellence*. (Ellershaw J & Wilkinson S. eds.), Oxford University Press, Oxford. p. 42 – 61
- Haber J. (2010) Sampling. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice* 7<sup>th</sup> edn. (Lobiondo-Wood G. & Haber J., eds), Mosby Elsevier St. Louis.
- Hockley J, Dewar B & Watson J (2005) Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life.' *Journal of Research in Nursing* **10**, 135 – 151.
- Jack B., Gambles M., Murphy D. & Ellershaw J.E. (2003) Nurses' perceptions of the Liverpool Care Pathway for the dying patient in the acute hospital setting. *International Journal of Palliative Nursing* **9**(9), 375 – 381.
- Jones M. & Rattray J. (2010) Questionnaire design. In *The Research Process in Nursing*, 6<sup>th</sup> edn. (Gerrish K. & Lacey A., eds), Wiley-Blackwell, Oxford.
- Kinder C. & Ellershaw J. (2003) How to use the Liverpool Care Pathway for the Dying Patient. In *Care of the Dying: A pathway to excellence*. (Ellershaw J & Wilkinson S. eds.), Oxford University Press, Oxford. p. 11 – 41.
- Lee P. (2005) The process of gatekeeping in health care research. *Nursing Times* **101** (32), 36.
- Lhussier M., Carr S. & Wilcoxson J. (2007) The evaluation of an end of life integrated care pathway *International Journal of Palliative Nursing* **13** (2), 74 – 81.

Lobiondo-Wood G. & Haber J. (2010a) Introduction to Quantitative Research. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice* 7<sup>th</sup> edn. (Lobiondo-Wood G. & Haber J., eds), Mosby Elsevier St. Louis. p. 157 – 176.

Lobiondo-Wood G. & Haber J. (2010b) Reliability & Validity. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice* 7<sup>th</sup> edn. (Lobiondo-Wood G. & Haber J., eds), Mosby Elsevier St. Louis. p. 285 – 308.

McKeown A., Cairns C., Cornbleet M. & Longmate A. (2010) Palliative care in the intensive care unit: an interview based study of the team perspective. *International Journal of Palliative Medicine* **16** (7), 334 – 338.

McKeown K., Haase T., Pratschke J., Twomey S., Donovan H., & Engling, F. (2010) *Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, Report 5, Final Synthesis Report*, Dublin: Irish Hospice Foundation. Available at <http://www.hospicefriendlyhospitals.net>

Parahoo K. (2006) *Nursing Research: Principles, Process and Issues*, 2<sup>nd</sup> edn. Palgrave Macmillan, Houndsmill.

Polit D.F. & Beck C.T. (2010) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*, 7<sup>th</sup> edn. Wolters Kluwer Health / Lippincott Williams & Wilkins, Philadelphia.

Preston M. (2007) The LCP for the dying Patient: a Guide to Implementation. *End of Life Care* **1**(1), 61 – 68.

Proctor S, Allan T. and Lacey A. (2010) Sampling. In *The Research Process in Nursing*, 6<sup>th</sup> edn. (Gerrish K. & Lacey A., eds), Wiley-Blackwell, Oxford.

Quality standards for end-of-life care in hospitals: Making end-of-life care central to hospital care. Dublin: Irish Hospice Foundation, 2010.

Robson C. (2007) *How to do a Research Project: a guide for undergraduate students*. Blackwell Publishing, Oxford.

Sullivan-Bolyai S. & Bova C. (2010) Data Collection Methods. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice* 7<sup>th</sup> edn. (Lobiondo-Wood G. & Haber J., eds), Mosby Elsevier St. Louis.

Trinity College Dublin (2010) *Guidelines for preparing a research proposal*. TCD, Dublin.

Thompson G., McClement S. & Daeninck P. (2006) “Changing lanes”: facilitating the transition from curative to palliative care. *Journal of Palliative Care* **22** (2), 91 – 98.

Toscani F., Di Giulio P., Brunelli C., Miccinesi G., & Laquintana D. (2005) How people die in hospital general wards: a descriptive study. *Journal of Pain and Symptom Management* **30** (1), p. 33 – 40

van der Riet P., Good P., Higgins I. & Sneesby L. (2008) Palliative care professionals' perceptions of nutrition and hydration at the end of life. *International Journal of Palliative Care* **14** (3), 145 – 150.

Walker R. & Reid S. (2010) The Liverpool Care Pathway in intensive care: an exploratory study of doctors and nurses perceptions. *International Journal of Palliative Nursing* **16** (6), 267 – 272.

Walters S. & Freeman S. (2010) Descriptive analysis of Quantitative data. In *The Research Process in Nursing*, 6<sup>th</sup> edn. (Gerrish K. & Lacey A., eds), Wiley-Blackwell, Oxford.

Watson J., Hockley J. & Dewar B. (2006) Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal of Palliative Care* **12** (5), 234 – 239.

Willard C. & Luker K. (2006) Challenges to end of life care in the acute hospital setting. *Palliative Medicine* **20**, 611 - 615.

## Bibliography

Al-Qurainy R, Collis E and Feuer D (2009) Dying in an acute hospital setting: the challenges and solutions. *International Journal of Clinical Practice* **63** (3), 508 – 515.

Bach V., Ploeg J. & Black M. (2009) Nursing roles in end-of-life decision making in critical care settings. *Western Journal of Nursing Research* **31**, 496-512.

Curtis J.R., Patrick D.L., Engelberg R.A., Norris K., Asp C. & Byock I. (2002) A measure of the quality of dying and death: initial validation using after-death interviews with family members. *Journal of Pain and Symptom Management* **24** (1), 17-30.

Department of Health UK (2008) NHS End of Life Care Strategy: *Promoting high quality care for all adults at the end of life*. Retrieved from: [http://www.dh.gov.uk/en/Healthcare/IntegratedCare/Endoflifecare/DH\\_299](http://www.dh.gov.uk/en/Healthcare/IntegratedCare/Endoflifecare/DH_299)

Ellershaw J., Smith C., Overill S., Walker S. & Aldridge J. (2001) Care of the dying: setting standards for symptom control in the last 48 hours of life. *Journal of Pain and Symptom Management* **21** (1), 12 – 17.

Ellershaw J. & Murphy D. (2005) The Liverpool Care Pathway (LCP) influencing the UK agenda on care of the dying. *International Journal of Palliative Nursing* **11** (3), 132 – 134.

Hamilton, F. & McDowell, J. (2004) Identifying the palliative care role of the nurse working in community hospitals: an exploratory study. *International Journal of Palliative Nursing* **10** (9), 426 – 433.

Health Service Executive and Irish Hospice Foundation (2006) *Care for People Dying in Hospital in Ireland*. Irish Hospice Foundation, Dublin.

Health Service Executive and Irish Hospice Foundation (2008) *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks*. Irish Hospice Foundation, Dublin.

Middlewood S., Gardner G. & Gardner A. (2001) Dying in hospital: Medical failure or natural outcome? *Journal of Pain and Symptom Management* **22** (6), 1035 – 1040.

Mirando, S., Davies, D. & Lipp, A (2005) Introducing an integrated care pathway for the last days of life. *Palliative Medicine* **19**, 33 – 39.

National Care of the Dying Audit (UK) – Hospitals (NCHAH): *Round 2 Generic Report 2008/2009*. Retrieved from: <http://www.liv.ac.uk/mcp cil/Liverpool-care-pathway/national-care-of-the-dying-audit.htm>

National Council for Palliative Care (2005) *Changing Gear: Guidelines for Managing the Last Days of Life in Adults*. National Council for Palliative Care, London.

Searle C. & McInerney F. (2008) Nurses' decision-making in pressure area management in the last 48 hours of life. *International Journal of Palliative Nursing* **14** (9), 432 – 438.

The Marie Curie Palliative Care Institute Liverpool, (2009). The *Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation: LCP generic document V.12*. Received directly on request from source through e-mail: [lcp.enquiries@rlbuht.nhs.uk](mailto:lcp.enquiries@rlbuht.nhs.uk)

van der Heide A., Veerbeek L., Swart S., van der Ridt C., van der Maas P. & van Zuylen L. (2010) End-of-life decision making for cancer patients in different clinical settings and the impact on the LCP. *Journal of Pain and Symptom Management* **39** (1), 33 – 42.

Veerbeek L., van Zuylen L., Swart S.J., van der Maas P.J., de Vogel-Voogt E., van der Heide A. & van der Rijt C. (2008 a). The effect of the Liverpool care pathway for the dying: a multi-centre study. *Palliative Medicine* **22**, 145 – 151.

Veerbeek L., van Zuylen L., Swart S.J. & Jongeneel G. (2008b) Does recognition of the dying phase have an effect on the use of medical interventions? *Journal of Palliative Care* **24** (2) 94 - 102

# Appendix 1

## **Search Strategy**

In October 2010, a search of the international literature on care-of-the dying was conducted in electronic databases CINAHL, PUBmed, Sage, ProQuest, Internurse and Ovid. (as well as library textbooks) in the period 2003 – 2010. The inclusion criteria were adult populations and English language. Research articles based in hospices and nursing homes were included as they produced relevant findings. Search results show that there has been extensive research on care of the dying examined mainly from the qualitative perspective. Nine empirical articles from these searches have been reviewed (8 qualitative and 1 quantitative).

Manual searches of Trinity Library and the Irish Hospice Foundation Library (the Thérèse Brady Library) were also conducted. One article (qualitative) from the TCD search and two articles (1 qualitative and 1 quantitative) from the IHF search were reviewed.

**Search Words:** ‘dying phase’, ‘comfort measures for the dying’, ‘symptom control in care of the dying patient’ and ‘integrated care pathway for the dying’.

### ***Range of articles:***

The articles gathered ranged from 2003 to 2010. The articles were mainly sourced in England but some were sourced in Scotland, Denmark, Canada, the United States of America and Australia.

A clinical practice development article and a seminal book on end-of-life care have also been reviewed. Strategies for care of the dying were retrieved from literature in the Health Service Executive, the Irish Hospice Foundation, the Department of Health (UK), the National Council for Palliative Care (U.K.) and the Marie Curie Foundation Liverpool U.K.

## Appendix II

### Outline of the Liverpool Care Pathway

#### ❖ Origin

The Liverpool Care Pathway (LCP) was developed in the late 1990's as a means of transferring best practice in care of the dying from the hospice setting to other sectors in health care. The LCP was developed by the Royal Liverpool University Trust and the Marie Curie Centre Liverpool and it has been recognized as a model of good care and was awarded NHS Beacon Status in 2000. The NHS Beacon Programme identifies centres of excellence and supports the delivery of high-quality patient-centred care by spreading good practice across the NHS (Jack *et al.* 2003)

#### ❖ Format

The Liverpool Care Pathway is a multi-professional document that provides an evidence-based framework and measurable outcomes of care in the last days of the patient's life. It focuses on the assessment of comfort measures, anticipatory prescribing of medication and discontinuation of inappropriate interventions as well as psychological and spiritual care (Gambles *et al.* 2006).

#### ❖ Commencement of the LCP for the dying patient

Once the multidisciplinary health care team decide that the patient is dying the LCP is commenced. The decision that the patient has entered the dying phase is based on the presence of two of the following four criteria: the patient is bed-bound, is semi-comatose, is only able to take sips of fluid or is no longer able to take tablets (Jack *et al.* 2003)

#### ❖ Assessment of patient's comfort in the dying phase (Gambles *et al.* 2006)

##### **Initial assessment**

<b>Goal 1</b>	Current medication assessed and non-essentials discontinued
<b>Goal 2</b>	As required subcutaneous drugs written up according to protocol (pain, agitation, respiratory tract secretions, nausea and vomiting, dyspnoea)
<b>Goal 3</b>	Discontinue inappropriate interventions (blood tests, antibiotics, IV fluids, or drugs, document 'not for CPR', deactivate cardiac defibrillators)
<b>Goal 4</b>	Ability to communicate in English assessed as adequate (patient/carer)
<b>Goal 5</b>	Insight into condition assessed with patient and carer:
<b>Goal 6</b>	Religious and spiritual needs assessed with patient and carer.

##### **Ongoing assessment**

<b>4 hourly</b>	Pain, agitation, respiratory tract secretions, nausea, and vomiting, dyspnoea, mouth care, micturition, medication given safely and accurately, syringe driver checked (where appropriate)
<b>12 hourly</b>	Mobility, bowels, psychological, religious/spiritual

## Appendix III

### Part A: Questionnaire on attitudes

**Directions:** Tick the box under the opinion that most closely represents your own.

1. Nurses are capable of identifying that a patient is dying.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. I would not like the responsibility of identifying a patient as dying.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Nurses cannot cease routine care for the dying patient without permission from a doctor.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. The length of time taken to care for a dying patient is vitally important.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Nurses should not give dying patients honest answers about their condition.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. End stage palliative care does not do anything for the patient.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. The focus of care should be adapted when death becomes imminent.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. When a patient has been identified as dying a 'do not resuscitate order' should be placed on his/her chart.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Nurses play a key role in helping patients die in comfort.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Comfort care for the dying patient should not replace routine nursing practice.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. I would not like to care for a dying patient.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Comfort care will enhance the dying patient's quality of life.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Specialist palliative care teams are never necessary to deal with a dying patient.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Symptom control for the dying patient is not the nurse's responsibility.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. When nursing a dying patient it is good practice, when possible, to frequently ask them about symptom control.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. Symptom control guidelines are necessary for delivering optimal end-of-life care.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Nurses cannot manage symptom control in the dying phase.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. The dying patient's physical needs should be decided by them when possible.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. Dignity of a patient is not more important than effective care.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Administration of opioids by means of a syringe driver is often an essential measure in symptom control.

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Part B: Knowledge Questionnaire

Please answer all the following questions by ticking the appropriate box to indicate the answer you consider to be correct. Tick one box only.

1. The decision that a patient is dying should be made by a multidisciplinary team.

Correct

Incorrect

2. There is a need for specialist palliative care teams to be involved with every dying patient.

Correct

Incorrect

3. The dying person should not be allowed to make decisions about his/her physical care.

Correct

Incorrect

4. Treatment procedures should be continued even when the patient is dying.

Correct

Incorrect

5. Routine nursing practice should not take precedence over a patient's comfort.

Correct

Incorrect

6. Dehydration is a normal part of the dying process.

Correct

Incorrect

7. Frequent repositioning of a dying patient is not always desirable.

Correct

Incorrect

8. When a patient is diagnosed as dying current medication should be reassessed and non-essentials discontinued.

Correct

Incorrect

9. Use of opioids is appropriate to control pain for the dying patient.

Correct

Incorrect

10. Symptoms of increased chest secretions and terminal agitation are unavoidable in dying patients.

Correct

Incorrect

11. Regulation of bowel movements is often a problem for a dying patient.

Correct

Incorrect

12. Retention of urine is more likely than urine incontinence in the dying patient.

Correct

Incorrect

13. All dying patients will be at high risk of skin breakdown.

Correct

Incorrect

14. Breathless is a common symptom in the dying phase.

Correct

Incorrect

15. General comfort care should not take precedence over skin care.

Correct

Incorrect

16. Maintaining a fluid balance record for the dying patient is important.

Correct

Incorrect

17. The dying patient should not be coaxed to eat.

Correct

Incorrect

18. It is appropriate to control pain in the dying phase by use of both analgesia and sedation.

Correct

Incorrect

19. An acute episode in a chronically ill patient may represent a terminal event.

Correct

Incorrect

20. Reducing the respiratory rate can relieve breathlessness for the dying patient by reducing anxiety.

Correct

Incorrect

## Part C: Experience survey

### Section 1

Please answer each question by ticking the appropriate box.

1. Please indicate your number of years nursing experience.

1-5 years	5-10 years	10-15 years	15-20 years	>20 years
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2. Have you received pre-registration education in end-of-life care?

Yes

No

3. Have you received post-registration education in end-of-life care?

Yes

No

### Section 2

The following section concerns your experience in delivering comfort care to dying patients. Please indicate your answer to the question by placing a number in the box which corresponds to your experience (see answer guide).

**Answer guide:**

- 0 never**
- 1 1– 5 times**
- 2 5–10 times**
- 3 10–15 times**
- 4 15– 20 times**
- 5 > 20 times**

- 1 I have been present as a nurse when a patient has died.
- 2 I have been in charge of nursing care for a dying patient.
- 3 I have used an integrated care pathway for end-of-life care.
- 4 I have been part of an interdisciplinary team that identified a patient as dying.
- 5 I have collaborated with an interdisciplinary team in delivering end-of-life care for a dying patient.
- 6 I have nursed a dying patient with a do not resuscitate order.
- 7 I have set up a syringe driver for subcutaneous administration of anticipatory prescribed medications to a dying patient.
- 8 I have administered prescribed opiate drugs to a dying patient to control pain.
- 9 I have administered prescribed drugs to a dying patient to control respiratory secretions.
- 10 I have administered prescribed drugs to a dying patient to control breathlessness.
- 11 I have been involved in cessation of artificial hydration for a dying patient.

- 12 I have been involved in cessation of artificial feeding for a dying patient.
- 13 I have dealt with nausea and vomiting episodes for a dying patient.
- 14 I have managed constipation problems for a dying patient.
- 15 I have inserted a urinary catheter to manage urine retention for a dying patient.
- 16 When caring for a dying patient I have been involved making the decision to cease routine care and focus on comfort care.
- 17 I have managed physical comfort measures for a dying patient with the provision of an air mattress.
- 18 I have discussed the prognosis of dying with a patient in the dying phase
- 19 I have acted as advocate for a dying patient when he/she needed their wishes to be heard regarding treatment.
- 20 I have negotiated a cessation of diagnostic interventions for a dying patient

Thank you for taking the time to complete this questionnaire. I sincerely value the important contribution that you have made to knowledge development in this area.