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Instruments used to measure the effectiveness of palliative care education initiatives at the undergraduate level: A systematic literature review

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Abstract

Background: The increase in the numbers of patients with palliative care needs has resulted in growing pressures on the small number of specialist palliative care providers within the New Zealand context. These pressures can potentially be eased by ensuring an adequately trained workforce, beginning with undergraduate training in the healthcare field. The goal of the present review is to ascertain what tools exist to measure the effectiveness of undergraduate palliative care education initiatives.

Method: A systematic review of both qualitative and quantitative literature was undertaken. Searches within ERIC, CINAHL Plus, Medline and Medline in Progress and Google Scholar databases were conducted for the period 1990-2011. A checklist adapted from Hawker et al. (2002) was utilised to select and assess data.

Results: Fourteen of the 112 articles met the inclusion criteria. Overall inconsistencies in the amount of validation information provided and a narrow focus on aspects of palliative care competence was apparent. No universally applicable validated questionnaire to assess the effectiveness of undergraduate palliative care education could be identified.

Conclusion: The increased focus by educational institutions on instilling palliative care skills in healthcare students necessitates the development of comprehensive and validated tools to evaluate the effectiveness of education initiatives.

Keywords: programme, assessment, evaluation, effect, impact, education, palliative care, terminal care, nursing undergraduate and student.

What instruments have been used to measure the effectiveness of palliative care education initiatives at the undergraduate level? A systematic literature review

Background

An ageing population coupled with advances in the treatment of chronic degenerative diseases, is likely to lead to an increased demand for health professionals who are well educated in the knowledge and skills required to provide quality care to those diagnosed with a life limiting illness ¹. The changing nature of palliative care has also seen a rise in its demand. In particular, older people are more likely than younger people to die from cardiovascular diseases, stroke, some cancers (e.g. prostate cancer), and following neurological conditions, such as Parkinson's disease and dementias.² Data indicates that these conditions typically have a very different dying trajectory than cancer, ³ the disease for which models of palliative care were originally developed.⁴ In response, palliative care has evolved to include a wide array of treatments and therapies, provided across diverse settings including acute care, intensive care, emergency services as well as hospice and home-based care.⁵ Given these trends, there is a recognition both nationally and internationally of the necessity of redesigning palliative care services to better meet patient and family/whanau needs, as demonstrated by the generation of new policies and guidelines for the incorporation of palliative care into the health services.^{6, 7, 8)} With an estimated 380 full-time specialist palliative

care providers across New Zealand, there is mounting pressure on this small group to cater to this growing need in addition to providing education and support to the 100,000 generalistⁱ palliative care providers.⁹ International studies have identified that ‘generalists’ often feel ill equipped to manage patients’ palliative care needs and, in particular, struggle with identifying when a palliative approach may be appropriate.^{10, 11, 12} This growing demand can potentially be addressed by ensuring an adequately trained workforce, beginning with undergraduate healthcare training. According to Keating and Teed,¹³ “Growing social demand for skills in the provision of palliative care services places pressure on health professional courses to produce exemplary graduates” (p 5). Various authors have offered suggestions as to the content for undergraduate palliative care training including: an understanding of the basic principles of palliative care, appropriate interventions, planning and assessment as well as an understanding of both the diversity and inter-professional team working of clinical specialisations in the delivery of palliative care.¹³ Several authors have also recommended the inclusion of education surrounding loss and grief in order to facilitate both the ability to offer psychosocial support for patients and their families as well as aid in the development of coping skills for health professionals working in this area

ⁱ Generalist palliative care has been defined as “*palliative care* provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team....It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams”¹⁴

^{15,16,17} A training needs analysis (TNA) conducted by the National End of Life Care Programme and Connected in the UK reported that “while most health staff have some involvement in end of life care, few had received more than basic level training in this sensitive and challenging area.”¹⁸

With an increased focus on instilling appropriate skills in healthcare students, a growing number of institutions are introducing palliative care education initiatives throughout their undergraduate curriculum. Despite this increase, a great deal of debate, both nationally and internationally still surrounds the adequacy of current programmes in preparing tomorrow’s health professionals with the requisite knowledge, skills and attitudes to competently deliver palliative care. Internationally, research has indicated continued deficiencies in undergraduate palliative care education in relation to programme availability, structure and content.^{19,20} These findings have resulted in the development of a number of measurement tools designed to identify ‘gaps’ in current programmes as well as to inform recommendations for the future curriculum development. The evaluation of the impact of undergraduate palliative care education poses both methodological and measurement challenges.²¹ While much work has been devoted to measuring changes in undergraduate student attitudes, knowledge and skills, to date there is no common agreement on universally applicable measurement tools. The aim of the present critical literature review was therefore to identify and evaluate the existing questionnaire tools.

Aim

To identify instruments which have been used to assess the effectiveness of palliative care education initiatives at the undergraduate level, and to consider the psychometric properties of those instruments.

Methods

A systematic review of quantitative and qualitative literature was undertaken using a framework developed by Hawker and Payne.²² This framework was considered to be suitable as it provided a review structure adaptable to a range of methodological approaches. The review was conducted in the following stages: (1) search strategy; (2) inclusion criteria; (3) assessment of relevance; (4) data extraction and appraisal; and (5) data synthesis.

Search Strategy

The goal of this research was to conduct a systematic and comprehensive review of published evidence related to the selection/inclusion criteria. A list of keywords was developed by consensus among the reviewers, and relevant databases were searched including: ERIC, CINAHL Plus, Medline and Medline in Progress and Google Scholar, for the period 1990 to 2011. Keywords included: programme, assessment, evaluation, effect, impact, education, palliative care,

terminal care, nursing undergraduate and student. Wild card searches were used to account for word variations.

Inclusion criteria

Inclusion criteria were developed through a process of consultation between the reviewers. Consideration for inclusion required the following: 1) the topic of the research must measure skill and knowledge development and/or attitudinal change following participation in a palliative care education programme and 2) the research participants must be students at the undergraduate level. The literature was further limited to peer-reviewed articles published in English between 1990 and 2011. Both qualitative and quantitative research was eligible for inclusion.

Assessment of relevance

To achieve the final selection, three systematic and objective stages of assessment were utilised examining in turn the title, abstract and body of the paper. An initial scoping exercise, conducted by HN involved reviewing the title, and where necessary, abstract of the retrieved search items. Independent assessments of the retrieved literature by the two reviewers HN and RF were conducted utilizing a checklist developed by Hawker et al.²² These assessments were then compared and any disagreements were discussed and resolved.

Results

A total of 14 out of an initial 112 articles met the inclusion criteria for this review. Excluded articles were not relevant to the identified criteria (See Figure 1). Of the included articles, seven of the studies included instruments that assessed undergraduate nursing students²³⁻²⁹ three studies included tools that assessed medical undergraduates,³⁰⁻³² while one study included measures designed for physiotherapy undergraduates.³³ Of the remaining studies: one assessed healthcare and medical undergraduates³⁴ and two studies^{35,36} included instruments designed to assess persons from a range of disciplines. Three of the articles were based on studies conducted in the UK^{23,30,31}; six were conducted in the U.S^{24,26,27,28,32,35}; one was conducted in Canada²⁵; one in Australia³⁶; two in India.^{29,33} and one in Hungary.³⁴ The results of the review are presented below as both a summary and evaluation in light of the research objective. The 14 identified articles reported on the use or development of 13 questionnaire tools.

[Figure 1 here]

Overview of the instruments

The majority of studies utilised pre-existing instruments.^{23,24,25,26,27,30,31,34,36} One of the studies used an instrument that was developed in the sixties,⁽³⁶⁾ two studies used instruments that were developed in the seventies^{25,34}, two were developed in the eighties,^{25,27} two were developed in the nineties^{24,30} and four were developed from 2000 onwards.^{26,31,33,35} Two of these studies modified the

tool to fit the purpose of their research either by changing the terminology used or the question format.^{35, 36} A small number of the studies included original measures.^{26, 28, 29, 32, 33}

Indicators

The studies assessed in the review utilised a variety of indicators to measure the effectiveness of palliative care education. Four of the studies included measures of the medical knowledge attained by the participants an indicator of programme effectiveness.^{23 26, 29, 33} Attitudes/opinions related to palliative care delivery were also assessed.^{24, 26, 27, 28, 32, 33, 35} Perceptions of confidence in dealing with issues related to palliative care delivery were also utilised as an indicator of attained competence^{30, 31} as well as frequency of experience in palliative care delivery.³³ Finally a number of studies examined attitudes and emotional reactions to death and dying.^{24-27, 30-32 34, 35}

Content

Theoretical knowledge was assessed by Arber et al.²³ and Kwekkeboom et al.²⁶ using the Palliative Care Quiz for Nursing (PCQN).³⁷ Items focused on the philosophy, and principles of palliative care, the management of symptoms and psychosocial and spiritual care of individuals and families. Velayudhan et al.²⁹ developed multiple choice questionnaires: one version for medical students which

contained 20 items, and one version for nursing students which contained 15 items. The focus was predominantly on theoretical knowledge although also included some psychosocial open-ended questions such as “what is quality of life?” Kumar et al.³³ employed the Physical Therapy in Palliative Care – Knowledge, Attitudes, Beliefs and Experiences Scale (PTiPC-KABE Scale)³³ to research critical care nurses. The 37-item self-report measure consisted of both quantitative and qualitative data relating to the participants perceived knowledge (as well as attitudes, beliefs and experiences of palliative care).

Changes to participant’s confidence levels associated with providing palliative care were measured by Mason and Ellershaw^{30, 31} using the Self-Efficacy in Palliative Care Scale (SEPC).³⁸ The 23-item SEPC contains three distinct subscales (communication, patient management, and multi-professional team work). Lack of confidence in one’s abilities can negatively impact on performance.³⁹ A study by Yetterberg et al.⁴⁰ indicated that the self-assessed confidence of medical students correlated with performance on a variety of interventions and competence assessment measures.

A plethora of educational studies over the last decade have demonstrated the importance of positive attitudes to learning.⁴¹⁻⁴⁴ Attitudinal data around providing end of life care was similarly assessed in the included studies. In addition to use of the PCQN, Kwekkeboom et al.²⁶ included a 12-item scale designed by Bradley et al.⁴⁵ to assess physician and nurses’ attitudes about care at

the end of life. The domains covered included: views about roles and responsibilities of health care professionals in caring for terminal patients, the extent to which palliative care provides additional benefits not offered in conventional medical care, views about the role, and importance of clinician-patients communication.

Previous studies have demonstrated that students who have completed clinical rotations and courses in palliative care expressed more comfort with death and caring for dying patients.⁴⁶⁻⁴⁸ To address this aspect of effective education, Kwekkeboom et al.²⁶ assessed nursing students concerns about caring for dying patients using a 6- item scale designed by Milton⁴⁹ representing major areas of concern to nursing students. Participants were asked to rate their degree of comfort when dealing with a dying patient and their family members, ability to locate resources needed to care for a dying patients, and ability to handle their own emotions.

Barrerre et al,²⁴ Frommelt³⁵ and Mallory²⁷ all utilised the Frommelt Attitude toward Care of the Dying (FATCOD)⁵⁰ instrument. FATCOD was developed by Frommelt in 1988 to assess nurses' attitudes toward caring for terminally ill individuals and their families. Schwartz et al.³² explored changes to participants' attitudes towards death using the Concept of a Good Death Measure.⁵¹ The instrument contains 17 descriptive positive statements relating to a "good" death. Based on the research by Walden-Galuszko and associates,⁵² the measure

incorporates the concepts of a “traditional” versus a “modern” death, and includes topics one might consider important at the end of life. Items were developed based on discussions with clinicians as well as a review of the lay and professional literature. The measure assesses three domains: closure, personal control, and clinical criteria.

Death anxiety was measured by Mason and Ellershaw^{30,31} using the Thanatophobia Scale (TS)⁵³ to measure attitudes and expected outcomes of providing care for palliative care patients. Hegedus et al.³⁴ employed the Multidimensional Fear of Death Scale (MFODS)⁵⁴ developed by Neimeyer and Moore in 1994 based on the work by Hoelter (1979). Drawing on Hoelter’s⁵⁵ definition of fear of death; “an emotional reaction involving subjective feelings of unpleasantness and concern based on contemplation or anticipation of any several facets related to death” (Hoelter⁵⁵ in Hegedus et al.³⁴, pg. 265). Hurtig et al.²⁵ used the Confrontation-Integration of Death Scale (CIDS) developed by Klug⁵⁶ and adapted by Chandler.⁵⁷ CIDS measures two areas of what Hurtig et al. describe as “the reconciliation with death construct”: “death confrontation” (contemplation of death), and “death integration” (the positive emotional response to death confrontation)²⁵ (pg. 31). Personal experience of death was accounted for using an open-ended question.

Schwartz et al.³² used the Concerns about Dying (CD) instrument.⁵⁸ The CD contains 10 descriptive statements designed to assess an individual's comfort level in caring for the dying as well as general concerns about death. The CD is split into three parts: general concerns about death and dying, spirituality, and concerns about working with the dying.

Mooney³⁶ used the revised Collett-Lester Fear of Death Scale,⁵⁹ originally created in 1969.⁶⁰ The instrument contains four subscales, each containing seven items focusing on items relating to one's own death or the death of others.

Structure

The format most commonly utilised across the included studies was a Likert-type scale with 12 of the 14 included studies incorporating this format. A 1-5 scale was most frequently used.^{24, 26, 27, 32-36} Hurtig and Stewin²⁵ included the Confrontation and Integration of Death scale (CIDS)⁵⁶ which used a 4 point scale in each of two subscales of 10 items (integration factor) and 8 items (confrontation factor) respectively. High scores correspond to the possession of a high degree of a factor. Kwekkeboom et al's²⁶ "Concerns about caring for dying patients" questionnaire also recorded responses in a 4 –point Likert-type format with 0 = "not at all" to 4 = "very much so". Higher scores indicated more concern / worry. The "Concept of a Good Death"⁵¹ measure utilized by Schwartz et al,³² incorporated a 4 point Likert format as well. The measure assessed the perceived essential components at the end of life among a number of dimensions including

spiritual peace, acceptance, freedom from pain, closure etc rated along scales ranging from 1 “not necessary” to 4 “essential”. The Thanatophobia scale⁵³ included in the studies by Mason and Ellershaw^{30,31} recorded responses along a 7 point Likert scale measuring the level of agreement with 7 statements of negative attitude towards caring for a dying patient. The “Completion Survey” measure designed by Thompson²⁸ assessed respondent confidence level in dealing with patients who are dying. The items consisted of four topics addressing level of comfort at the beginning of the educational intervention and repetition of those topics assessing level of confidence at the conclusion of the programme.

The Palliative Care Quiz for Nurses (PCQN)³⁷ incorporated in the studies by Arber²³ and Kwekkeboom et al²⁶ utilized a true/false/don't know format to measure nurse's knowledge of palliative care. Knowledge was also assessed by Velayudhan et al²⁹ utilizing a multiple-choice format. Finally the Self-Efficacy in Palliative Care Scale (SEPC)³⁸ incorporated by Mason and Ellershaw^{30,31} measured confidence in performing practice based objectives on a 100 mm Visual Analogue Scale.

Psychometric properties

Of the 14 reviewed articles two studies omitted validation information for included measures and five of the studies referenced previous validation of included tools. The amount of detail reported in the remaining articles also varied considerably. Kumar, Jim and Sisodia³³ reported the test-retest reliability for a

pilot of the PTiPC-KABE Scale for twenty-four participants. In contrast, the Self-Efficacy in Palliative Care (SEPC)³⁸ and Thanatophobia⁵³ scales were rigorously validated in the studies by Mason and Ellershaw.^{30,31} In terms of reliability data, internal consistency as measured by Cronbach's alpha was most often utilised.²⁴^{27,30,31,32,34-36} The Palliative Care Quiz for Nurses (PCQN)³⁷ utilized in both the Arber²³ and Kwekkeboom et al²⁶ studies was assessed for reliability by the authors of the measures using the Kuder-Richardson (KR-20) formula for dichotomous variables. The Confrontation-Integration of Death Scale (CIDS),⁵⁶ utilized by Hurtig and Stewin²⁵ was also assessed using the KR-20. Moderate-to-good psychometric properties in relation to reliability were reported for the validated instruments as indicated by the magnitude of the coefficients, ranging from .65 to .95. Split-half reliability for the Revised Collett-Lester Fear of Death Scale⁵⁹ utilized by Mooney³⁶ ranged from .72 to .91.⁶⁰ Test-retest reliability was demonstrated for a majority of the measures incorporated in the studies^{23,24,25,26,27,32,33,34,35,36} including: the PCQN,³⁷ FATCOD,⁵⁰ MFODS,⁵⁴ CIDS,⁵⁶ Attitudes about Care at the End of Life,⁴⁵ Revised Collett-Lester Fear of Death Scale,⁶⁰ PTiPC-KABE Scale,³³ Concept of a Good Death⁵¹ and Concerns about Dying⁵⁸ measures. Structural validity was demonstrated through principal component analysis for measures included in a three of the studies.^(26,30,31) Content validity was assessed for the FATCOD and FATCOD B^{50,61} as well as the Concerns about caring for dying patients²⁶ measure (Kwekkeboom, pers. comm.)

Practicality

Of the 14 included articles, 13 reported response rates of 60% or greater. The study by Schwartz et al³² reported a response rate of 90% for the interclerkship component of the study. In contrast, the response rate for the longitudinal elective component was 53%. Frommelt³⁵ reported the number of persons in both the control and experimental groups. The number of persons from whom the sample was drawn was not specified. A number of the studies incorporated longitudinal designs, each of which were subject to attrition in participant numbers in the post-test component.^{23, 24, 27, 34, 30, 31, 32, 36} Among the explanations for this attrition in the study by Barrere et al²⁴ was the listed loss of 9 students from the traditional programme (13% decrease) and five from the accelerated programme (11% decrease) as well the student's opting not to complete the follow-up questionnaire. Mason and Ellershaw^{30, 31} reported a small number of questionnaires returned with incomplete sections indicative of problems in formulating a response to some of the included items in both the 2008 and 2010 studies. The authors report no significant demographic differences (e.g. gender, previous experience) for this subgroup, although the analyses were not presented. Other issues associated with study measures include a lack of established validity for an instrument as cited by Kumar et al³³, although the research cited good test-retest reliability for the measure. Question wording was also an issue in the study by Arber²³ who cited problems with ambiguity in some of the questions found in

the PCQN³⁷ within the British context. Mallory²⁷ also noted a limitation of the included tool (FATCOD)⁵⁰ in its ability to identify all factors (e.g. all previous education, all death experiences) that could have impacted on the participants' attitudes toward care of the dying. Finally, Barrere et al²⁴ reported limitations in the forced-choice format of the included instrument preventing the respondents from elaborating on the rationale behind their selections.

Discussion

Evaluation of programme effectiveness is an essential component in the delivery of quality undergraduate palliative care education. Such evaluations can provide information valuable in assessing both individual achievement and programme success. Therefore the inclusion of valid instrument in the evaluation of undergraduate education in palliative care is essential. According to Meekin et al,⁶² the evaluation of a palliative care education programme's effectiveness: "should take into account the singularly broad range of knowledge, skills, and attitudes that must coalesce for a student to develop competence in the area" (p. 987-988). To some extent, the study measures reviewed have addressed on some of the areas outlined above. Questionnaire tools have ranged from the very specific in focus (Completion Survey²⁸) to more inclusive measures (PTiPC-KABE Scale³³). However no measure was located that comprehensively addressed *all* of the areas required in the effective assessment of palliative care competence. Furthermore, the focus of most of the measures is directed at students from a

narrow range of health professions. For example the PTiPC-KABE Scale³³ assessed the palliative care related knowledge, attitudes, beliefs and experiences of physical therapy students. Most frequently however the measures were directed towards assessing nursing students (Palliative Care Quiz for Nurses (PCQN)³⁷, Frommelt Attitudes toward Care of the Dying Scale for nurses (FATCOD⁵⁰), Confrontation-Integration of Death Scale (CIDS⁵⁶), Concerns about caring for dying patients questionnaire²⁶, Completion Survey²⁸, medical students (Self-efficacy in Palliative Care Scale (SEPC)³⁸, Concept of a Good Death,⁵¹ Concerns about Dying (CD)⁵⁸ or both Thanatophobia Scale⁵³, Attitudes about Care at the End of Life⁴⁵ questionnaire, Palliative Care Knowledge Questionnaire.²⁹ Two of the tools were directed at more diverse populations (FATCOD, Form B,³⁵ Revised Collett-Lester Fear of Death Scale⁵⁹)

A further issue concerns the fact that all of the included measures relied on self-report data to gauge the effectiveness of palliative care education. This type of data can provide valuable insights into acquired theoretical knowledge as well as provide documentation of changes in attitudes or perceptions of palliative care. However self-report data may not provide the best measure of behavioural competence in palliative care delivery, which is the objective of educational initiatives. Overall, self-assessment is by design both subjective and context dependent.⁶³ Self-reported abilities may vary from actual abilities^(64,65) and

therefore measures of this design are insufficient in providing an accurate accounting of both individual and programme effectiveness. In line with the issue of effective evaluation, a number of the included study measures focussed on the assessment of attitudes (e.g. FATCOD,⁵⁰ MFODS⁵⁴). While studies within healthcare have supported a link between attitude and behaviour,^(66, 67) behaviours are influenced by a number of factors other than just the particular attitude under study.^{68, 69, 70} Measurements of attitudes alone are therefore insufficient in achieving education evaluation goals.

Ultimately the measurement of the effectiveness of palliative care education initiatives cannot rely on the creation of one universal tool. One method of overcoming the shortcomings of existing measures as recommended by Weissman et al⁷¹ would be to correlate indicators of perceived levels of competence with observed performance such as in Objective Structured Clinical Examination Stations (OSCE's) as a means to evaluate the effectiveness of an educational programme. Although not without limitations, the method has been used extensively in the assessment of palliative care competency.⁷²⁻⁷⁴ In fact, the recommendations by Mason and Ellershaw³⁰ include the following comment: "the addition of observed structured clinical examinations (OSCEs) would strengthen this study and further validate the effects of the educational programme (p. 691)." Thus self-assessments should be complimented by reliable and valid external sources of information.^(63, 75) In essence a multidimensional approach to

assessment is required incorporating a variety of indicators and employing methodological triangulation to achieve a strategy capable of accurately assessing the effectiveness of palliative care initiatives at both the individual and programme level.

As with any other piece of research, this current review has a few notable limitations. Notwithstanding the comprehensive search, retrieval and review strategies employed, reviewed articles were limited to those published in English and the grey literature was not searched. However, no previous research examining the tools for effectively evaluating undergraduate palliative care programmes across diverse healthcare fields could be identified.

The growing pressure to produce healthcare professionals competent in the delivery of palliative care and the consequent proliferation of programmes to meet that need points to the necessity of developing research in this area.

Comprehensive and validated methodologies to assess both individual and programme development will be crucial to the success of these education initiatives. The findings of the present review provide evidence for the need for further work to achieve these goals.

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Appendix 1

Table 1: Summary of the included research articles

Authors	Study Aims	Participants	Setting	Method	Response Rate	Results
Arber (2001) ²³	<ul style="list-style-type: none"> To measure student nurses' knowledge of palliative care at the beginning and end of a module in palliative care using the PCQN. To identify significant changes in student nurses' knowledge of palliative care at the end of the module. 	Undergraduate nursing students	Kingston University, UK	Pre-test/post-test questionnaire	74%	Statistically significant increase in students' knowledge of palliative care following intervention (median 2.00) (Wilcoxon signed rank test; $p = 0.001$)
Barrere, Durkin & LaCoursiere (2008) ²⁴	Evaluation of the influence of the integration of the ELNEC curriculum into a baccalaureate nursing program on student's attitudes toward care of the dying	Senior baccalaureate nursing students	Quinnipiac University, Hamden, U.S	Pre-test/post-test questionnaire	71%	Attitudes towards care of the dying patient positively affected following intervention ($t = -5.977$, $p = .000$) Multiple regression analyses indicated that no previous experience with the terminally ill was the strongest predictor of a change in attitude from the beginning to the end of the program ($\beta = .332$, $p = .004$)
Frommelt (2003) ³⁵	To compare the relationship between an individual's attitude toward caring for terminally ill persons and their families, before and after participating in an educational program of study on death and dying.	Undergraduate students	Private Catholic liberal arts college, Midwestern U.S	Pre-test/post-test questionnaire	Not specified.	Significant change in attitude in the experimental group following intervention ($t = 7.283$, $p < 0.05$)
Hegedus, Zana & Szabó (2008) ³⁴	<ul style="list-style-type: none"> To assess improvement in death anxiety in medical students and health care workers attending 	Medical students and health care workers	Institute of Behavioural Sciences, Semmelweis University	Pre-test/post-test questionnaire	60% of consenting medical students 96% of	Reduction in most of the factors of fear of death and overall fear of death. Significant decrease in Fear of Conscious Death factor for women ($t = 0.050$, $p < .05$). Students aged between 22 and 30 demonstrated more significant changes in

	<p>courses in end-of-life care</p> <ul style="list-style-type: none"> To explore of the level of importance of various. attitudes related to death and dying To explore topics eliciting the strongest fear response. 		Budapest, Hungary		consenting health care workers	Fear for Significant Other ($t=0.009, p < .05$) and Fear of Conscious Death ($t = 0.055, p < .05$)
Hurtig & Stewin (1990) ²⁵	To examine the effect of death education and experience on nursing student's attitude towards death.	First level (no clinical experience) class of diploma nursing students	University of Alberta, Edmonton, Canada	Questionnaire administered following interventions.	72%	Death education increased awareness of death (68.8% in the didactic programme and 61.3% in the experiential group). Significant interaction between experience and type of programme ($F= 4.37, p = .016$). Experiential approach had a positive effect on the death confrontation of students with no personal experience with death but a negative impact on those who did ($F= 1.72, p = .018$)
Kumar, Jim & Sisodia (2011) ³³	To measure the changes in knowledge, attitudes, beliefs and experiences of student physiotherapists who attended a palliative care training program	Student physiotherapists	Academic Institution, India	Pre-post quasi-experimental design in which data were collected from a convenience sample through a self-administered questionnaire	68%	Statistically significant ($p < .05$) changes observed in knowledge (7.844.61 points), attitudes (9.468.06 points), beliefs (4.883.29 points) and experiences (15.811.28 points).
Kwekkeboom, Vahl, Eland (2005) ²⁶	To evaluate the impact of a Palliative Care Companion program.	Undergraduate nursing students	College of Nursing, University of Wisconsin-Madison, U.S	Pre-test/post-test questionnaire	87%	Significant increase in knowledge ($F = 4.69, p < .05$) and attitude ($F = 10.05, p < .01$) scores in the experimental group following intervention. Significant decrease in concerns about nursing dying patients ($F = 5.93, p < .05$)
Mallory (2003) ²⁷	<ul style="list-style-type: none"> To evaluate the effect of a palliative care educational component on the attitudes toward care of the dying in undergraduate nursing students. Examine the effect of previous education on 	Undergraduate nursing students	Two state universities in the Appalachian Mountains, North Carolina, United States	Quasi experimental, longitudinal design was used with a pre-test, intervention and double post-test format.	91%	Significant difference between measures of attitude toward care of the dying following intervention ($t = 3.85, p = .00$).

	attitudes toward care of the dying.					
Mason & Ellershaw (2008) ³⁰	To examine a short programme of education and a placement in a specialist palliative care unit will have a significant effect on: <ul style="list-style-type: none"> Perceived efficacy in caring for the dying patient Perceived outcomes in caring for the dying patient 	Fourth year medical undergraduates	University of Liverpool Medical School, UK	A pre- and post-survey was completed using a composite questionnaire, comparing two cohorts	Cohort 1 = 65% Cohort 2 = 69.5%	Statistically significant improvements in SEPC and TS scores for both cohorts (communication, cohort 1 $t=-16.53$ /cohort 2 $t=-34.74$, patient management, cohort 1 $t=-22.19$ /cohort 2 $t=-39.58$, multidisciplinary team-working, cohort 1 $t=-15.72$ /cohort 2 $t=-26.14$, Thanatophobia, cohort 1 $z=-7.6$ /cohort 2 $z=10.33$).
Mason & Ellershaw (2010) ³¹	To examine a short programme of education and a placement in a specialist palliative care unit will have a significant effect on: <ul style="list-style-type: none"> Perceived efficacy in caring for the dying patient Perceived outcomes in caring for the dying patient	Undergraduate nursing students	University of Liverpool Medical School, UK	A pre- and post-survey was completed using a composite questionnaire A purposively selected Focus group	64%	Significant improvements following intervention in perceived efficacy (communication $t=-16.41$, $p<0.001$; patient management $t=-22.31$, $p<0.001$; multidisciplinary teamwork $t=-15.56$, $p<0.001$); and Thanatophobia ($z=-7.51$, $p<0.001$).
Mooney (2005) ³⁶	To examine the effectiveness of a death education program in reducing death anxiety	Undergraduate medical undergraduates	Griffith University Gold Coast Campus	Pre-post test.	90%	Decrease noted in death anxiety following intervention based on observed differences in mean scores. (No inferential statistical test results presented).
Schwartz, Clive, Mazor, Ma, Reed & Clay (2005) ³²	To evaluate the effectiveness of two validated measures in detecting attitude change caused by two EOL curricula: a year-long Elective and a day-long Inter-Clerkship for medical undergraduates	BSN nursing students	University of Massachusetts Medical School	A case control design and a one group pre-test/post-test design.	Elective = 53% Interclerkship = 90%	Post-elective there was less concern about working with dying patients (adjusted change score -0.45 , $p<0.0001$) and decrease in general concern (adjusted change score -0.17 , $p<0.10$). Following the interclerkship students' patient based concerns about death decreased ($t=-1.96$, $p=0.054$). No statistically significant changes seen in spiritual beliefs or general concerns about death, or in the valuation of closure or clinical palliative care.

Thompson (2005) 28	To assess the degree of change in comfort level that students experienced during the time that they participated in an EOL course	Nursing Students	Jefferson College of Health Sciences, Roanoke, Va.	A questionnaire was completed on the final day of class	100%.	Increase in average comfort scores from 4.8/10 pre-intervention to 7.5 indicating nearly a 30% improvement.
Velayudhan, Ollapally, Upadhyaya, Nair & Aldo (2004) 29	To evaluate the effectiveness of a newly introduced palliative care training course through evaluation of student's knowledge of care.	Third year nursing students, 4 th year medical students	St John's National Academy of Medical Sciences, Bangalore, India	Pre-test, post-test one and post-test two with questionnaires	90%	Improvement seen in knowledge scores following intervention (9.08 to 10.43, $p < 0.05$). Post-test two scores not significantly different from the pre-test (8.43) or control group (8.36).

Appendix 2

Table 1: Characteristics of adopted measures

Authors	Components	Description	Development	Psychometric Properties	Example Items
Arber (2001) ²³ Kwekkeboom, Vahl, Eland (2005) ²⁶	Palliative Care Quiz for Nurses (PCQN) Concept: nurses level of palliative care knowledge Target population: student nurses	20 items Domains: <ul style="list-style-type: none"> Philosophy and principles of palliative care Management of pain and other symptoms Psychosocial and spiritual care of individuals and families Scoring: dichotomous true/false items (1= right. 0 = wrong/don't know) Administration method: self-administered	Developed by Ross, McDonald & McGuinness ³⁷ informed by the work of Dieckmann et al ⁷⁶ and Pratt et al ⁷⁷ in Alzheimer's disease knowledge testing.	Internal consistency: Utilising the Kuder-Richardson (KR-20) formula for dichotomous variables: .78 Ross, McDonald & McGuinness ³⁷ Test-retest reliability .56 Ross, McDonald & McGuinness ³⁷	1. Palliative care is only appropriate in situations where there is evidence of irreversible deterioration. 2. The analgesic effect of other opioids is measured against that of morphine. 3. The extent of the disease determines the methods of pain management.
Barrere, Durkin & LaCoursiere (2008) ²⁴ Mallory (2003) ²⁷	Frommelt Attitudes toward Care of the Dying Scale for nurses (FATCOD) Concept: nurses' attitudes toward caring for terminally ill persons and their families Target population: student nurses	30 items Domains: <ul style="list-style-type: none"> Attitudes towards patient Attitudes towards family members Scoring: 5-point Likert Scale Made up of an equal number of positively and negatively worded items	Developed by Frommelt ⁵⁰ . Informed by Wiczorek's Attitude Towards Nursing Care of the Dying Child scale as cited in Ward and Fetler ⁷⁸ personal experience and concerns expressed by nurses at workshops ⁶¹	Content validity index (CVI) was computed (1.00). Determination of interrater agreement was computed (0.98) ⁶¹ Test-retest reliability (n = 18) with scores compiled and then computed using Pearson Product-Moment Correlation Coefficient (r=.94). Second test-retest conducted using sample of 30 (r=0.90) ⁶¹ Internal consistency score (alpha coefficient) 0.89 ⁷⁹	4. Nursing care for the patient's family should continue throughout the period of grief and bereavement. 5. I would not want to be assigned to care for a dying person. 6. The nurse should not be the one to talk about death with the dying person.

<p>Hegedus, Zana & Szabó (2008) ³⁴</p>	<p>Multidimensional Fear of Death Scale (MFODS)</p> <p>Concept: emotional reactions to several facets related to death</p> <p>Target population: medical students and health care workers</p>	<p>42 items</p> <p>Domains:</p> <ul style="list-style-type: none"> • Fear of dying process • Fear of the dead • Fear of being destroyed • Fear for significant others • Fear of the unknown • Fear of conscious death • Fear for the body after death • Fear of premature death <p>Scoring: 5-point Likert Scale</p> <p>Fear of Dying (six items)</p> <p>Fear of the Dead(six items)</p> <p>Fear of Being Destroyed (four items)</p> <p>Fear for Significant Others (six items)</p> <p>Fear of the Unknown (five items)</p> <p>Fear of Conscious Death (five items)</p> <p>Fear for the Body After Death (six items)</p> <p>Fear of Premature Death (four items)</p>	<p>Developed by Hoelter ⁵⁵</p>	<p>Mean reliability coefficient = .75 ⁵⁵</p> <p>Neimeyer and Moore ⁵⁴</p> <p>Cronbach's α of .65 to .82 for eight subscales</p> <p>test-retest (3 week period) .61 to .81 ⁸⁰</p>	<p>1 = Strongly agree 2 = Mildly agree 3 = Neither agree nor disagree 4 = Mildly disagree 5 = Strongly disagree</p> <p>1 2 3 4 5 1. I am afraid of dying very slowly.</p> <p>1 2 3 4 5 2. I dread visiting a funeral home.</p> <p>1 2 3 4 5 3. I would like to donate my body to science.</p> <p>1 2 3 4 5 4. I have a fear of people in my family dying.</p>
<p>Hurtig & Stewin (1990) ²⁵</p>	<p>Confrontation-Integration of Death Scale (CIDS)</p> <p>Concept: death confrontation (the conscious contemplation of of one' one death) and death integration (the positive emotional assimilation of the consequence of death confrontation)</p> <p>Target population: student nurses</p>	<p>18 items</p> <p>Domains:</p> <ul style="list-style-type: none"> • Death confrontation • Death integration <p>Scoring :</p> <p>Total score range of 0-72</p> <p>death confrontation: subscale: 0-32,</p> <p>death integration subscale: 0-40</p> <p>4 point Likert-type scale</p>	<p>Developed by Klug ⁵⁶</p> <p>Reformulated to Klug Death Acceptance Scale (KDAS) ⁸¹</p>	<p>Test-retest reliabilities: confrontation items .59 integration items .55</p> <p>Internal Consistency –(Kuder-Richardson-20 coefficients) of .81 and .85.</p> <p>Discriminant validity: Templar Death Anxiety Scale Confrontation -.11 Integration .16 ⁵⁶</p>	<p>1. I avoid discussing death when the occasion presents itself.</p> <p>2. When possible, I will attend the funeral of a deceased friend.</p> <p>3. I enjoy life more as a result of facing the fact of death.</p>

<p>Kwekkeboom, Vahl, Eland (2005) 26</p>	<p>Attitudes about Care at the End of Life questionnaire</p> <p>Concept: Clinician roles and responsibilities Attitudes toward palliative care Attitudes toward clinician-patient communication</p> <p>Target populations: physicians, nurses</p>	<p>12-item Domains:</p> <ul style="list-style-type: none"> • Role of healthcare professionals in caring for terminally ill • Views on palliative care • Views on clinician-patient communication <p>Scoring: 5-point Likert Scale (strongly disagree-strongly agree) Negative items reverse coded.</p>	<p>Developed by Bradley, Cicchetti, Fried, Rousseau, Johnson-Hurzeler, Kasl et al. 45</p>	<p>Test-retest reliability, Cronbach's α (.86). Factor analysis – 9/12 had loading > 0.50. The results suggest 3 factors: Professional Responsibility, Perceived Efficacy of Hospice and Physician-Patient Communication 45</p> <p>Modified version recorded Cronbach's α < .38 Time 1 & Time 2 82</p>	<p>Physicians do not have a role in hospice care</p>
<p>Mason & Ellershaw (2008) 30</p> <p>Mason & Ellershaw (2010) 31</p>	<p>Self-efficacy in Palliative Care Scale (SEPC)</p> <p>Concept: perceived efficacy in caring for the dying patient</p> <p>Target population: undergraduate medical students</p>	<p>Participants rate their confidence in performing practice based objectives on a 100 mm Visual Analogue Scale. 23-items in the three sub-scales assessing perceived efficacy.</p>	<p>Developed by Barrington & Murrie 38</p>	<p>Cronbach's α of 0.84-0.85 recorded. Varimax rotated principal components analysis of the SEPC Scale suggested 3 distinct factors, as theoretically expected, with high factor loadings of 0.45-0.89 at pre- and post-test 30, 31</p>	<p>I would feel (very anxious to very confident) in relation to:</p> <p>Using the actual word cancer to impart the diagnosis</p>
	<p>Thanatophobia Scale</p> <p>Concept: attitudes and expected outcomes of providing care for palliative care patients.</p> <p>Target population: undergraduate medical students nursing students</p>	<p>7-item scale. Participants rate how much they agree / disagree with expressed negative attitudes on a 7-point likert scale. Greater cumulative scores indicate negative attitudes.</p>	<p>Developed by Merrill, Dales & Thornby. 53</p>	<p>Internal consistency Cronbach's α 0.92-0.95 Principal components analysis of the Thanatophobia Scale uni-dimensional factor solution. Factor loadings of 0.60-0.81 at pre- and post-test. 30, 31</p>	<p>When patients begin to discuss death, I feel uncomfortable.</p> <p>I don't look forward to being the personal nurse for a dying patient.</p> <p>Managing dying patients traumatizes me.</p>

<p>Mooney (2005) ³⁶</p>	<p>Revised Collett-Lester Fear of Death Scale</p> <p>Concept: overt (conscious) death fear and anxiety.</p> <p>Target population:, adults > 18 years.</p>	<p>Designed to measure overt (conscious) death fear and anxiety.</p> <p>Four subscales containing seven items.</p> <p>Scoring on a 5-point scale ranging from 5 “very”, 4-3-2 “somewhat” and 1 “not”</p> <p>The circled scores are summed for each 7-item subscale.</p>	<p>Collett-Lester Fear of Death Scale.⁶⁰</p> <p>Revised Collett-Lester Fear of Death Scale ⁶⁰</p> <p>Third version ⁵⁹</p>	<p>Test-retest reliability: 0.85 death of self, 0.79 dying of self, 0.86 death of others 0.83 dying of others Split-half reliability - 0.91, 0.89, 0.72, and 0.87 ⁶⁰ Third Version ⁵⁹ Internal Consistency Cronbach α's Death of Self, 0.91; Dying of Self, 0.92; Death of Others, 0.88; Dying of Others 0.92. Item-total correlations > .47</p>	<p>How disturbed or made anxious are you by the following aspects of death and dying? Your own death:</p> <ol style="list-style-type: none"> 1. The total isolation of death 2. The shortness of life 3. Missing out on so much after you die 4. Dying young 5. How it will feel to be dead 6. Never thinking or experiencing anything again 7. The disintegration of your body after you die
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Appendix 2

Table 2 Characteristics of author-developed instruments

<p>Frommelt (2003) ³⁵</p>	<p>Frommelt Attitudes toward Care of the Dying Scale (FATCOD, Form B)</p> <p>Concept: attitudes of all students from a variety of programmes toward care of the terminally ill and their families.</p> <p>Target population: students from a range of programs of study</p>	<p>30 items</p> <p>Domains:</p> <ul style="list-style-type: none"> • Attitudes towards patient • Attitudes towards family members <p>Scoring: 5-point Likert Scale Made up of an equal number of positively and negatively worded items</p>	<p>Developed by Frommelt in 1988 ⁵⁰ and altered for study by Frommelt in 2003 ³⁵.</p>	<p>Content validity index re-computed for altered tool using judges as participants. Interrater agreement of 1.00 was computed. ³⁵</p> <p>Test-retest (.92). ³⁵</p>	<ol style="list-style-type: none"> 1. Giving care to the dying person is a worthwhile experience. 2. Death is not the worst thing that can happen to a person. 3. I would be uncomfortable talking about impending death with the dying person.
<p>Kumar, Jim & Sisodia (2011) ³³</p>	<p>Physical therapy in palliative care-knowledge, attitudes, beliefs and experiences scale (PTiPC-KABE Scale)</p> <p>Concept: palliative care knowledge, beliefs, attitudes and experiences</p> <p>Target population: physical therapy students</p>	<p>37 item self report measure collecting quantitative and qualitative data</p> <p>Domains:</p> <ul style="list-style-type: none"> • Knowledge • Attitudes • Beliefs • Experiences of palliative care <p>Scoring: 5-point Likert-type scale (strongly disagree-strongly agree)</p>	<p>Developed by Kumar, Jim & Sisodia ³³ based on the Neonatal Palliative Care Attitudes Scale by Kain, Gardiner and Yates ⁸³</p>	<p>Test-retest reliability (ICC=.80-.90) using 24 participants.³³</p>	<p>I feel a sense of personal failure when a patient dies</p>
<p>Kwekkeboom, Vahl, Eland (2005) ²⁶</p>	<p>Concerns about caring for dying patients questionnaire</p> <p>Concept: Concerns about caring for a palliative care population</p>	<p>6 item scale representing major areas of concern to nursing students.</p> <p>Scoring on 4-point scale with 0 = not at all to 4 = very much so. Higher scores indicate more concern / worry.</p>	<p>Developed by Kwekkeboom, Vahl, Eland. ²⁶ Based on the major areas of concern to nursing student outlined by Milton ⁴⁹</p>	<p>Content validity assessed by three palliative care experts (Kwekkeboom, pers. comm.)</p> <p>Time 1 Cronbach's α .87 Time 2 Cronbach's α .89 ²⁶</p>	<p>How concerned or worried are you about...</p> <ol style="list-style-type: none"> 1. providing emotional support to grieving families 2. providing emotional support to dying patients 3. being able to provide postmortem care

	Target population: nursing students				4. psychological effects on oneself 5. being able to maintain composure when working with dying patients 6. being able to provide physical care for dying patients
Schwartz, Clive, Mazor, Ma, Reed & Clay (2005) 32	Concept of a Good Death measure Concept: subjective components of a good death Target population: medical undergraduates	17 descriptive statements assess three domains; <ul style="list-style-type: none"> • Closure • Personal control • Clinical criteria Scoring: 4-point Likert-type scale ranging from 1 “not necessary” to 4 “essential”.	Developed by Schwartz, Mazor, Rogers, Ma & Reed, 51	Item frequency distributions and Cronbach’s alpha’s ($\alpha = 0.75, 0.83, \text{ and } 0.62$). Moderately high stability over a 14-day retest period ($ICC = 0.66, 0.83, \text{ and } 0.70$). 51	That family and doctors follow the person’s wishes. (Closure) That there be mental alertness until the end. (Personal Control) That it be painless or largely pain-free. (Clinical Criteria)
	Concerns about Dying (CD) instrument Concept: comfort level in working with dying patients and general concerns about death. Target population: medical undergraduates	10 descriptive statements assess three domains: <ul style="list-style-type: none"> • anxiety in dealing with death and/or dying patients: • general concern about death, spirituality, • concerns about working with dying patients Scoring: 5-point Likert type scale ranging from 1 “disagree completely” to 5 “agree completely”	Developed by Mazor, Schwartz, & Rogers 58	Test-retest reliability ($r = -.84, 0.89, 0.83$), internal consistency ($\alpha = 0.73, 0.76, 0.85$). 32	I get anxious or uncomfortable when I think about my own death. (General) I believe that my soul or spirit will continue after death. (Spiritual) I am worried about how I will react emotionally to dying patients (Patient-related).
Thompson (2005) 28	Completion Survey - Level of Palliative Care Delivery Comfort Concept: changes in perceived confidence in palliative care delivery based on course participation Target population: undergraduate nursing students	Participants were asked to rate their comfort level based on a scale from 0 to 10 on which 0 = completely uncomfortable and 10 = completely comfortable. 6 items included ratings of pre and post course confidence in: <ul style="list-style-type: none"> • Ability to care for dying patient • Ability to locate resources • Ability to handle emotions Item 7 Course approval rating	Developed by Thompson 28	No validation information provided.	At the beginning of this course I felt confident in my ability to care for a dying patient and his/her family. At the conclusion of this course I felt confident in my ability to care for a dying patient and his/her family.

		<p>Item 8 Free response regarding beneficial aspects of course</p> <p>Participants provided additional data on another form such as their age, nursing specialty, number of years in nursing, etc. (Thompson, pers. comm.)</p>			
<p>Velayudhan, Ollapally, Upadhyaya, Nair & Aldo (2004) 29</p>	<p>Palliative Care Knowledge Questionnaire</p> <p>Concept: impact of education course on palliative care-related competencies</p> <p>Target populations: medical students nursing students</p>	<p>Medical student version: 20 items. Nursing student version: 15 items. Multiple-choice format: Domains assessed:</p> <ul style="list-style-type: none"> • Pain and symptom assessment and treatment • Ethical and legal aspects of end of life care • Communication skills • Personal reflection • Psychosocial, spiritual and cultural aspects of death and dying • Working as part of an interdisciplinary team 	<p>Developed by Velayudhan, Ollapally, Upadhyaya, Nair & Aldo 29</p>	<p>No validation information provided.</p>	<p>Sample question for nurses:</p> <p>The effectiveness of nurse – patient communication is best validated by:</p> <p>(a) Client’s feedback (b) health team conference (c) Patient’s physiologic adaptation (d) Medical assessment (e) Improvement in health.</p> <p>Sample question for medical students:</p> <p>Paracetamol is:</p> <p>a. Centrally acting b. Peripherally acting c. Anti-inflammatory d. a & b e. a & c</p>

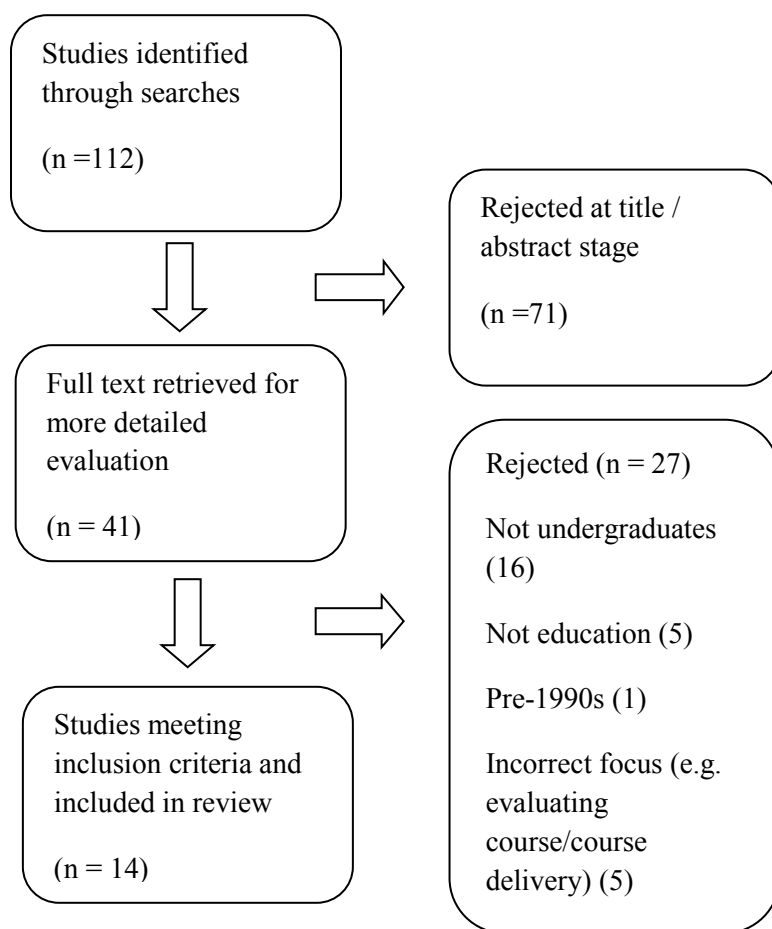


Figure 1: Flow chart of the included literature.