

**Does simulated experience of caring  
for a dying patient and their family  
improve the confidence and  
preparedness of medical students?**

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## **Abstract**

**Background:** Of all doctors, Foundation Year 1 (FY1) trainees spend the most time with dying patients and report feeling poorly prepared and lacking in confidence with respect to providing care to the dying. Despite documented effectiveness of simulation in teaching end of life care to undergraduate nurses, undergraduate medicine continues to teach this subject using a more theoretical, classroom-based approach. By increasing undergraduate exposure to interactive dying patient scenarios, simulation presents a potential opportunity to improve the confidence and preparedness of medical students to care for dying patients.

**Primary aims:** To explore whether simulated experience of caring for a dying patient and their family can improve the confidence and preparedness of medical students to provide such care.

**Methods:** Three studies were undertaken: a systematic review of the literature to ascertain what is known about the confidence of medical students to care for dying patients; a cross-sectional survey of medical student attitudes at Brighton and Sussex Medical School (BSMS) towards caring for a dying patient (Thanatophobia); and a mixed-methods interventional study simulating the care of a dying patient with pre/post measures of confidence (Self Efficacy in Palliative Care (SEPC) tool) and preparedness (Thematic Analysis (TA) of Focus Group data).

**Results:** The systematic review found medical students experience low baseline confidence to care for dying patients, with evidence that additional teaching interventions can statistically improve their confidence. Lack of exposure to dying patients and inadequate education at undergraduate level were cited as main factors affecting confidence.

332 (46.4%) students returned the cross-sectional study. A higher degree of thanatophobia was observed in younger students ( $p=0.004$ , CI -0.473 – -0.091) and those in their second year of study ( $p<0.001$ , CI 3.778 – 8.398). Gender identity and degree status had no effect on thanatophobia.

Thirty-eight fourth-year students participated in the simulation study. Low pre-simulation confidence echoed systematic review findings. A statistically significant post-simulation increase in confidence was seen for all three SEPC domains, with sustained confidence observed at six-months. Six themes were

identified from focus group data: current preparedness, simulated learning environment, learning complex skills, patient centeredness, preparation for the future and curriculum change. Students reported feeling better prepared to care for the dying and felt the simulations would be a worthy addition to the current curriculum at BSMS.

**Conclusion:**

Using simulation to teach medical students how to care for a dying patient and their family increases student confidence and preparedness to provide such care.

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## List of acronyms

APM	Association for Palliative Medicine
BSMS	Brighton and Sussex Medical School
COPD	Chronic Obstructive Pulmonary Disease
COREQ	Consolidated Criteria for Reporting Qualitative Research
CVC	Central Venous Catheter
FY1	Foundation Year One
GMC	General Medical Council
KS	Kolmogorov-Smirnov
NICE	National Institute for Health and Care Excellence
OSCE	Objective Structured Clinical Examination
PP Plot	Probability-probability plot
PPE	Patient and Public Engagement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
QQ plot	Quantile-Quantile plot
SEPC	Self-Efficacy in Palliative Care
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
TA	Thematic Analysis
TS	Thanatophobia Scale
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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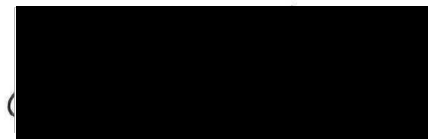
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At the start of my MD we were living in a different world. The COVID-19 pandemic has changed so much in the past ten months. I provided my support where I could through temporary secondment to the COVID-19 workforce. Being involved in the care of dying patients part-way through my research emphasised the importance of having the confidence to provide timely and appropriate end of life care. There are no second chances. I therefore dedicate this thesis to my dying patients, past, present, and future.



## **Declaration**

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

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Geoffrey Howard Wells

11<sup>th</sup> October 2020

## Chapter 1: Introduction

The past few decades have seen a continued increase in life expectancy within the United Kingdom (UK). In 1981 life expectancy was estimated to be 70.9 years for males and 76.9 years for females, increasing to 79.3 and 82.9 years respectively by 2018.<sup>(1)</sup>

The ability for humans to live longer, and to do so with control over chronic illness is largely attributed to advances in modern medicine. The idea of 'fighting' disease is one that is commonly held by patients, with contemporary views of death and dying often being represented as an unexpected or unwarranted outcome of illness.<sup>(2)</sup> It is not uncommon to read headlines referring to someone having 'lost their battle' with illness, and this may serve to demonstrate that despite improvements in medical science and an attitudinal change within society, death and dying remains a certainty for us all. By the end of 2017 there were 533,253 registered deaths in England and Wales, the leading cause of which were related to dementia and Alzheimer's disease.<sup>(3)</sup>

Living longer with chronic illness often leads to increasingly complex clinical situations in those who are in the last year of life, and those who are dying.<sup>(4)</sup> The number of hospital deaths is expected to rise significantly over the next decade as a result of our ageing population,<sup>(5)</sup> and as a result many medical and surgical teams need to prepare to care for an increasing number of dying patients.

It has been demonstrated that early recognition of dying leads to better outcomes for both patients and their families,<sup>(6)</sup> and provides us with the opportunity to address complex symptoms such as nausea, pain, and shortness of breath alongside the psychosocial and spiritual needs of the actively dying patient in a proactive rather than reactive manner.<sup>(7)</sup> However, things are not always that simple, and the ability to recognise when someone is dying is not a skill that all doctors possess.<sup>(8)</sup> It is suggested that this may be a reflection of a lack of prognostic training at undergraduate level, with limited teaching on recognising the dying process.<sup>(9)</sup> Studies have looked at the value of online training in teaching students how to recognise the dying patient, but found that initial improvements in students' prognostic skills were short lived, possibly due to students not appreciating the clinical relevance.<sup>(10)</sup>

Provision of basic palliative care is the responsibility of every doctor,<sup>(11)</sup> however of all qualified doctors, it is the most junior members who spend the greatest time with dying patients.<sup>(12)</sup> For many years the General Medical Council (GMC) have published clear recommendations that all medical students should receive core teaching on how to care for the dying.<sup>(13, 14)</sup> Despite this, recent studies demonstrate that Foundation Year 1 (FY1) doctors do not feel well-prepared to deliver basic palliative care, and in some cases report high levels of distress when doing so.<sup>(15)</sup> In 2019 a systematic review was undertaken to identify junior doctors' experiences of palliative care provision. Results of this review were concerning, with many junior doctors experiencing significant distress and anxiety following their involvement in caring for dying patients, with some even experiencing quantifiable levels of post-traumatic distress.<sup>(16)</sup> The review also discovered that whilst many junior doctors feel adequately prepared to care for the dying with the appropriate support of colleagues, this preparedness appears to deteriorate when they are required to provide such care when less support is available, such as during on call and out of hours duties.<sup>(16)</sup>

There is evidence within the literature that points towards there being a paternalistic approach to the clinical teaching of medical students with respect to dying patients. Some students perceive that they are kept away from dying patients by senior medical staff and nursing staff, and often excluded from being present at the bedside review of a dying patient as part of a routine teaching ward round.<sup>(12)</sup> Often students feel they are expected to clerk and present those patients deemed by senior doctors to be more interesting and demonstrating 'better' clinical signs which will allow students to pass their exams, whilst recognising that palliative care is only likely to feature in medical school examinations in a small way if at all.<sup>(17, 18)</sup> As a result, dying patients and those with palliative care needs are sometimes overlooked.<sup>(12)</sup> Some studies also suggest that students attached to specialist rotations are less likely to receive such teaching if the senior clinicians themselves have a lack of confidence to care for the dying, therefore tending to leave that aspect of patient care to their more junior colleagues.<sup>(19, 20)</sup>

What appears to exist is a misalignment between what is expected of our newly qualified doctors, and the preparation they have received at undergraduate level with respect to palliative care teaching.

## 1.1 Clarification of terminology

The importance of using correct terminology becomes apparent when estimating a patient's likely prognosis. Healthcare professionals often require an accurate-as-possible prognosis to be made to help determine what treatments can and should be offered to patients. In turn knowledge of the likely prognosis will help patients and families decide on the acceptability of those treatments they are offered.<sup>(21)</sup> It is incorrect to use terms such as 'palliative care', 'end of life', 'terminally ill', and 'actively dying' in an interchangeable way, as doing so can lead to situations where patients are inappropriately offered treatments that will be of no benefit to them, or are denied treatments that have the potential to offer many advantages in terms of symptom management.

### 1.1.1 Palliative Care

Much confusion exists around the correct use of the term 'palliative care' not only amongst the public, but also between healthcare professionals and within healthcare literature.

As defined by the World Health Organisation (WHO), palliative care is:

'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual' <sup>(22)</sup>

Life-threatening illness is not limited to cancer alone, but encompasses any illness which may be expected to shorten somebody's life. Examples of which include heart failure, motor neurone disease, dementia and chronic obstructive pulmonary disease (COPD) to name a few.

Furthermore, palliative care is often thought to be synonymous with dying, the result of which is that in some cases patients and families decline the support of palliative care as they feel it signifies imminent death. Palliative care may be appropriate at any stage in a person's illness, and in some cases is offered alongside curative treatment.<sup>(23)</sup> Failure of some healthcare colleagues to

understand the role and value of palliative medicine can occasionally mean patients with palliative care needs are not referred early enough in their disease trajectory.<sup>(24)</sup> In some cases a patient may not be referred at all, which may result in a failure to identify and address unmet palliative care need prior to death.

### 1.1.2 End of life

The National Institute for Health and Care Excellence (NICE) define 'end of life' quite broadly, and refer to those people who have advanced, progressive, incurable conditions whom may be expected to die within the next 12 months. It also includes those who develop acute life-threatening conditions,<sup>(25)</sup> for example a significant myocardial infarction or stroke.

Whilst palliative care includes the care of those considered to be at the end of life, it also includes the care of those who are not necessarily expected to die within the next 12 months.

### 1.1.3 Terminal Care, Dying, and Actively Dying

Terminal care generally refers to a broad time-frame of patient management, with patients being in the last few days, weeks or months of life from a point at which it becomes clear that they have begun to progressively decline.<sup>(26)</sup>

By definition dying is:

'a poorly understood phenomenon characterised by a gradual systemic shutdown, followed by an absence of criteria that define life' <sup>(27)</sup>

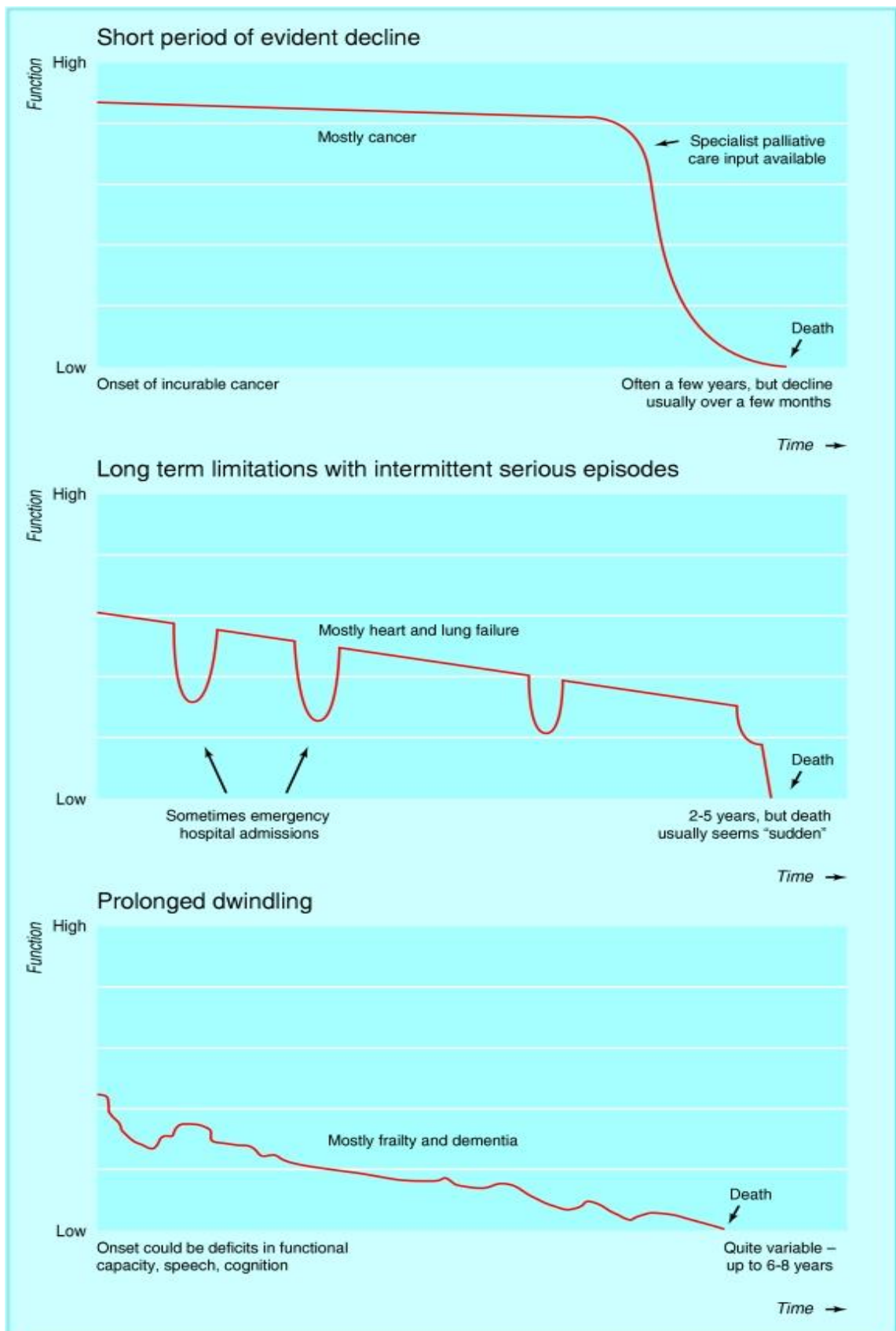
Actively dying tends to confer a much shorter time-frame within the dying process, and is defined as the hours or days prior to imminent death during which time the patient's physiological functions decline.<sup>(28)</sup>

## 1.2 Dying in the hospital setting

Over half of all UK deaths occur in a hospital setting,<sup>(29)</sup> with at least 12% of all inpatients being in the terminal phase of their illness.<sup>(30)</sup> Whilst competent and compassionate care of the dying is important for patients and their families, sadly many patients continue to die in hospital with unmet palliative care needs.<sup>(31)</sup> Even after a diagnosis of dying has been made, timely and accurate assessment of a patient's physical, psychological, social and spiritual needs is essential if there is to be any hope of identifying unmet needs on an individual basis. Such assessment may be made with direct involvement of the patient themselves, who

may remain conscious right through to the last few hours before death. However, the assessment of an unconscious patient requires astute observational skills to identify changes in facial expression or breathing pattern that may indicate discomfort or pain whilst performing a physical examination, as well as discussion and involvement of family members and nursing staff about specific care needs.<sup>(31)</sup>

The way people die is likely to differ depending on the underlying cause (Figure 1.1).<sup>(32)</sup> Patients dying as a result of cancer tend to have a smoother, downward, somewhat predictable trajectory, whereas those suffering with non-cancerous conditions (e.g. heart failure, COPD) often develop sudden relapses which can lead to a much quicker dying phase.<sup>(31)</sup>



**Figure 1.1 Typical trajectories for people living with progressive chronic illness**

### 1.3 Role of the doctor in caring for the dying patient

#### 1.3.1 The multidimensional nature of care

The essence of good quality palliative care centres around the ability to recognise, assess and manage complex symptoms in those who are living with a life-limiting illness, and to be able to do so at different stages within their disease trajectory. This takes skill and practice, and the doctor who is able to do this has the ability to make improvements to the quality of life of such patients.<sup>(7)</sup>

Figure 1.2 illustrates the multi-dimensional nature and complexities that someone who is at the end of their life may experience, and these are all areas in which the average junior doctor is likely to be involved given that death and dying occur in almost all areas of medicine.<sup>(12)</sup>

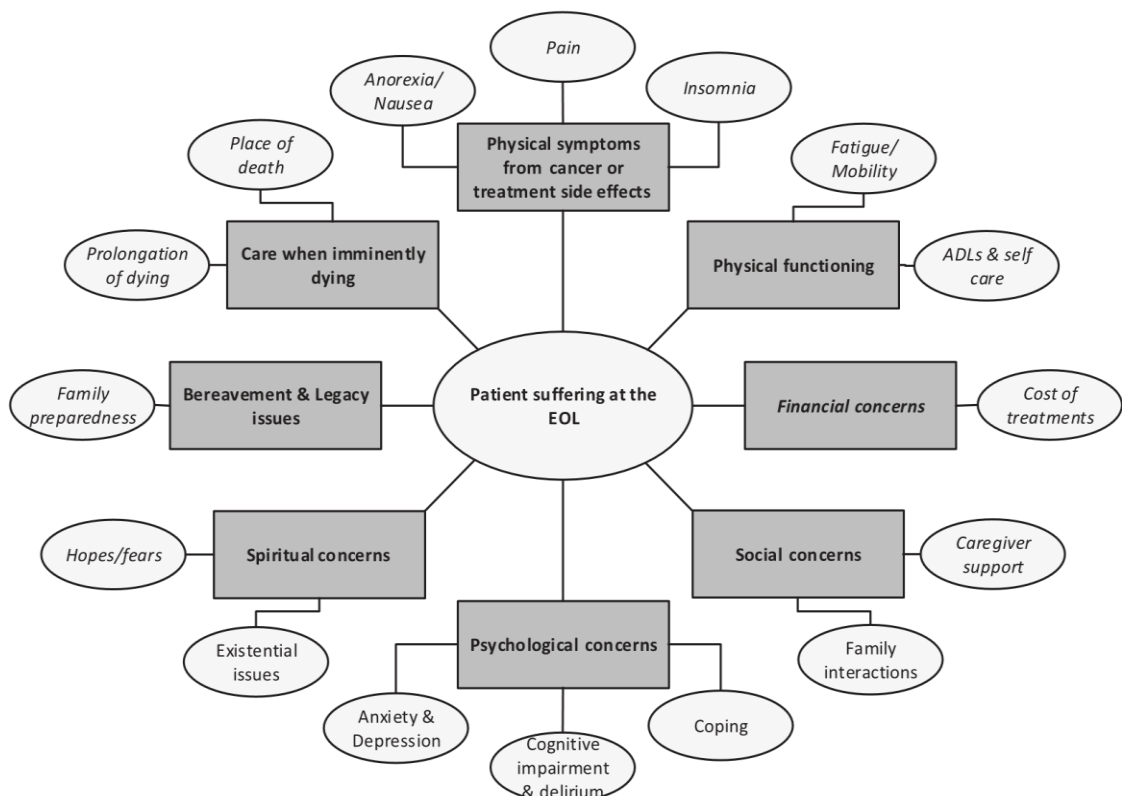


Figure 1.2 Multidimensional causes of patient suffering at the end of life



### 1.3.2 Recognition of dying

It is known that doctors are poor at recognising when a person is dying, and this is very much a skill that takes time to develop. <sup>(31)</sup> The importance of this skill becomes apparent once healthcare workers have been involved in the care of a dying patient, with the realisation that there is often a short window of opportunity with which to discuss those things that are of greatest importance to the patient, such as where they want to be cared for and where they want to die. Whilst this may be a little easier to approach in those who experience a stepwise deterioration in health, it becomes challenging in those patients who may suddenly deteriorate (Fig 1.1). Therefore, it is imperative that recognition of dying, or at least the recognition of the possibility of death in the near future, should occur earlier rather than later to allow these challenging discussions to take place working with the advantage of time rather than against it.<sup>(31)</sup>

### 1.3.3 Good prescribing practice

Often junior doctors will be asked to rationalise those medications a dying patient is currently taking. For example, it may remain appropriate for someone to continue an anti-anginal medication for as long as they are able to, as stopping it may bring on the return of previously well controlled chest pain. In contrast it may not be appropriate for that same individual to continue taking their cholesterol lowering medication, as it will not have any benefit to them at this stage of their illness, and may in fact be causing unwanted side effects as well as adding to their tablet burden.

### 1.3.4 Addressing spiritual and psychosocial needs

It is not uncommon for patients to develop high levels of distress when their disease progresses,<sup>(33)</sup> and it is important to recognise such distress may be of a psychological or spiritual nature.<sup>(34)</sup> Approximately one third of palliative care patients will experience depression, adjustment disorder and anxiety,<sup>(35)</sup> and so it is important that junior doctors are able to recognise psychological distress, and consider seeking advice from the wider team and psychiatry colleagues.

Whilst junior doctors would not be expected to have expert skill in the assessment and management of spiritual needs, the ability to recognise the presence of an unmet need is essential, prompting referral to the chaplaincy team who are at hand to provide skilled, holistic support irrespective of whether a person follows

a specific religion or not. In addition, the chaplaincy team will be able to provide specialist spiritual and religious support that many junior (and senior) doctors will not be best placed to provide. It is worth remembering that spirituality often interacts with culture, and on occasion one may conflict with the other which may result in psychological distress within the patient.<sup>(36)</sup> Most healthcare settings have access to chaplaincy support, with many offering an on-call service should a patient or family require such support out of hours.<sup>(26)</sup>

### 1.3.5 Care of a dying patient's family

It will be necessary for junior doctors to speak with families about the impending death of a patient, and what that dying process is likely to look like at an individual level. On occasion the junior doctor may find themselves having to inform relatives that a patient has died during their absence.

Distress amongst junior doctors can sometimes relate to feeling unprepared to speak with the relatives, a skill which is often found to be particularly difficult.<sup>(37)</sup> On occasion junior doctors may find themselves having to speak with relatives they have never met, or about a patient they have never seen when working in an on-call capacity.<sup>(38)</sup> It can be argued that one of the ways a junior doctor can prepare and develop their skills in recognising death as well as communicating to families what dying may look like, is to have been given the opportunity to see this for themselves as part of their undergraduate training.

Preparation for such eventualities is better than avoidance. Identifying one's own thoughts about death and dying, as well as caring for dying patients, dealing with patient death, and communicating with dying patients and their families is a good start in the preparatory process.<sup>(36)</sup>

## 1.4 Death denial and the junior doctor

As human beings the knowledge of our inevitable death can often create challenges for us, with death denial and avoidance of the subject being seen as coping mechanisms.<sup>(39)</sup> Research conducted in the mid-20th century found that all too often doctors would not accept the idea some of their patients were terminally ill and would continue to actively treat the dying. By doing so would further reinforce the notion of the doctor being the patient's saviour.<sup>(40, 41)</sup> The idea of a modern death has been suggested, in a world where advances in

medical science and technology have often served to prolong life, and lead the 'fight' against death.<sup>(39)</sup> Yet again we find ourselves attempting to prevent the dying process, and at the same time potentially denying our patients a peaceful death.

One important factor to consider is the way in which medical students are taught, as this has the ability to contribute to the gradual emotional detachment that is sometimes seen amongst medical undergraduates. A good example of this has been seen through use of cadavers to teach anatomy which often occurs very early in medical school curricula. Many physicians remember their personal emotional response upon initial exposure to a cadaver during their anatomy lectures, often recalling that they received no enquiry as to their emotional well-being from tutors, nor any reference made to the cadaver as a person but rather more of a teaching tool.<sup>(42)</sup>

Fortunately, things have begun to change for the better, with recognition that emotional management is an essential part of any doctor's training. There are examples of where this is achieved through recognising and discussing the altruistic donation the person made in donating their body to medical education, allowing students to ask questions and explore their own feelings and emotions.<sup>(43)</sup> Medical students must be given opportunities to learn how to communicate their emotions in safe and protective environments, because the physician who is able to do this is in a far better position to be able to communicate effectively with their patients about death and dying.<sup>(39)</sup>

## **1.5 Current UK guidance on care of the dying**

In 2014 the Department of Health published new guidelines on how we should be caring for dying patients and those close to them. These guidelines were created in a collaborative effort by the Leadership Alliance for the Care of Dying People, made up of 21 separate organisations who were tasked with creating new guidance to replace the outgoing Liverpool Care Pathway.<sup>(44)</sup> The five priorities focus on:

1. Recognising the possibility that somebody may die in the next few days or hours
2. Communicating this sensitively to the patient and those identified as important to them
3. Involving the patient and those important to them with regards to treatment and care decisions
4. Actively exploring and respecting the needs of families and those important to the dying person, meeting these needs as far as possible
5. Creating an individual plan of care, including food and drink, symptom control, psychological, social, and spiritual needs.<sup>(45)</sup>

### **1.6 Junior doctor distress**

Studies have begun to highlight the levels of distress junior doctors face when caring for dying patients, and have explored some of the reasons why this might be. Gibbins et al (2011)<sup>(12)</sup> undertook a study where 21 newly qualified doctors (trained at 17 different UK medical schools) participated in semi-structured interviews to determine their experiences of undergraduate and postgraduate teaching and learning about palliative care and care of the dying. Participants reported a lack of exposure to dying patients and patients with palliative care needs during undergraduate training, a lack of formal examination in end of life care, and a heterogeneous exposure to palliative care teaching, all of which left them feeling under-prepared. In some cases, participants reported they had been unaware that they would be directly caring for dying patients as a Foundation Year 1 (FY1) doctor. In the postgraduate setting participants felt left alone and unsupported by senior medical colleagues in the management of palliative care and dying patients, instead learning by trial and error. They did, however, covet the experience of ward nurses who often guided FY1's through the complexities of caring for someone who is dying.<sup>(12)</sup>

In 2013 an Edinburgh study (Bowden et al)<sup>(15)</sup> sought to establish whether FY1 doctors were sufficiently prepared to deliver generalist palliative care. A total of 60 FY1 doctors completed a questionnaire assessing undergraduate experience, FY1 experience, and recommendations for future undergraduate training. Results echoed that of Gibbins' study, with the majority of FY1's responding that they felt

out of their depth when caring for a dying patient, often seeing a dying patient for the first time only after having qualified. Alarming 65% of respondents felt personally distressed when caring for patients with palliative care needs, with personal support mainly being received from friends and family rather than colleagues. This echoes another similar study which demonstrated that support after death generally came from other FY1 doctors, nurses, friends and family, with consultant or educational supervisor support being experienced only in the minority of cases.<sup>(46)</sup>

More recently, in 2019 Gajebasia *et al*/ conducted a qualitative study exploring the experiences of Foundation Year 1 and 2 doctors in caring for their dying patients. One of the three key themes that emerged from participants (n=47) focused on self-identified training needs, and particular reference was made to prescribing. Participants felt a lack of confidence in their prescribing skills for the dying, particularly when prescribing anticipatory end of life medications. There was a desire for further guidance to have been given at undergraduate level.<sup>(47)</sup>

This lack of confidence is not necessarily seen across the board, and there are studies both in the UK and abroad in which junior doctors report feeling confident to care for the dying.<sup>(48)</sup> However, in such studies those same doctors recognise that this confidence can take years to build up, with a strong push for palliative care training to continue to be delivered in the postgraduate setting.<sup>(49)</sup>

### **1.7 Palliative medicine teaching in undergraduate curricula**

If the undergraduate system appears to be failing to adequately prepare our junior doctors to care for the dying, it is important that we identify how medical schools teach palliative medicine, and care of the dying.

The structure and content of palliative care teaching within UK medical schools has been well documented. Reviews and reports from the turn of the 21<sup>st</sup> century concluded that palliative care teaching within undergraduate medical education lacked coordination and continuity with respect to both its delivery and content.<sup>(17, 50)</sup> Even as recently as 2010, studies have shown that significant heterogeneity remained between medical schools in terms of the amount of time dedicated to the topics of death, dying and bereavement, with some medical schools offering this teaching in the form of optional rather than compulsory lectures. Furthermore,

teaching coordinators found that due to the high competition for teaching time, they had little control over the method and timing of palliative care education delivery.<sup>(19)</sup>

In 2017 a systematic review looking at the content and method of undergraduate palliative care teaching worldwide found that whilst an increasingly consistent approach was being seen with respect to the delivery of palliative medicine curricula amongst medical schools, the method of delivery varied between institutions and countries. A broader range of teaching methods were being employed in the UK compared to other countries represented within the review, with increasing use of hospice placements, role-play and video being used to deliver teaching. Of the 124 studies included within the review, just four made reference to the use of simulation within undergraduate palliative care education, of which none were from the UK.<sup>(51)</sup>

In recent years, positive steps have been taken to align the palliative medicine components of medical school curricula with the recommendations set out by the GMC, which include evaluating the complexities, uncertainties and emotional challenges involved in caring for someone who is dying.<sup>(14)</sup> For several years the Association for Palliative Medicine for Great Britain and Ireland (APM) has produced a syllabus to guide medical schools in their content and delivery of undergraduate palliative medicine education, with regular updates and revisions having taken place over the last decade. Whilst it had been cited as a helpful tool by coordinators of palliative care teaching, the syllabus was found to be too long and as such there were issues incorporating it into existing undergraduate curricula which was already filled with content from all other specialities.<sup>(19)</sup> The curriculum has since been revised, with the 2014 iteration currently in place. In the past year or so the APM has begun the process of mapping this version of the curriculum to new GMC recommendations, with additional development of medical final examination questions to be incorporated into the medical licensing exam blueprint. The APM recognise that in many cases FY1 doctors will be required to apply the knowledge, skills and attitudes learnt at undergraduate level in relatively unsupervised situations during postgraduate clinical practice. Providing clarity through the mapping process will facilitate the coordinators of palliative medicine teaching in UK medical schools in ensuring GMC outcomes are represented within their school curricula.<sup>(52)</sup>

## **1.8 Simulation in palliative medicine education**

### **1.8.1 Hi-Fidelity simulation**

Advances in computer technology over the past forty years have led to the development of sophisticated full-scale mannequins. In today's world of medical education, mannequins have the ability to display a whole myriad of reactive physiological features such as breathing sounds, pulses, blood pressures, as well as have the ability to interact with users by way of voice transmitters and eye movements. Students are afforded the opportunity to learn from such a resource in a way that can provide an experience close to that of being at the bedside of a real patient, but in an environment where it is safe to make mistakes and learn from them.<sup>(53, 54)</sup>

Reviews on the value of simulation in medical education have demonstrated that repetitive practice involving medical simulations is associated with improved learner outcomes,<sup>(55)</sup> that it permits individualised learning that is adaptable with a valid approximation of clinical practice,<sup>(56)</sup> and that its value lies in the opportunity to garner feedback from teachers and peers.<sup>(57)</sup>

### **1.8.2 Death of the simulated patient**

Despite death and dying being natural events, it has been highlighted that healthcare students receive minimal exposure to death during undergraduate education.<sup>(58)</sup> In some specialisms such as nursing, increasing research has been conducted to argue the case for introducing care of the dying simulations into undergraduate training.<sup>(59)</sup>

In the postgraduate setting the death of a simulated patient is not a new concept, with many articles detailing the teaching to be gained in the disciplines of emergency care, paediatrics, and surgery,<sup>(58)</sup> however concerns have been raised about the effect simulator death may have on students. Whilst simulator death can provide an experience that is difficult to obtain in the clinical environment, facilitates practice in a safe environment, and provides opportunity for reflection and constructive feedback, there is concern that it has the potential to cause psychological harm to the student if they feel they were the cause of the death, and may therefore affect the perceived value of future simulation experiences.<sup>(60)</sup>

Whilst such concerns have merit, many can be mitigated by good preparation and planning of any simulated activity that includes patient death. Attention to detail in the pre-briefing stage would allow facilitators to review student expectations as well as respond to questions or concerns ahead of the simulated scenario. The debriefing stage allows students to voice their ideas, concerns and feelings relating to the scenario, and identify the learning that has taken place.<sup>(59-61)</sup>

### 1.8.3 Transfer of skills into clinical practice

In relation to the value of simulation in healthcare education, one key question arises: Do the skills taught and the learning that takes place actually transfer to clinical practice?

Studies have demonstrated that simulated learning does have the ability to transfer into clinical practice. Several practical skills can be taught in a simulator, for example. A single blinded study in 2010 sought to determine whether simulation training of ultrasound guided central venous catheter (CVC) insertion skills could improve insertion success rates in clinical practice. Medical students (n=185) were randomised to receive either didactic hands on teaching (n=90), or simulation training (n=95). Following training, blinded independent assessors observed 495 CVC insertions and found that those who received simulator training were significantly more successful inserting the CVC at their first attempt. Simulation training was demonstrated to be independently and significantly associated with first attempt success.<sup>(62)</sup>

The value of simulation not only exists in terms of practical skills, but also in overall patient care. A 2012 study reported on the use of simulation in a pre-registration nursing curriculum to develop students' performance in recognising and managing the deteriorating patient. Semi structured interviews were conducted with those students who had subsequently encountered deteriorating patients in clinical practice, and content analysis identified four key themes influencing the transfer of simulated learning to clinical practice; Ability to retrieve knowledge from memory of simulated practice and apply it to the clinical situation, the learning of mnemonics during the simulation and reapplication, comparing the clinical situation to that in the simulator and identifying similarities, and recognising emotional response to the situation and how it may affect clinical performance.<sup>(63)</sup>



The above two examples serve to provide the briefest insight as to the growing evidence that supports the transfer of skills learnt in simulation to clinical practice.

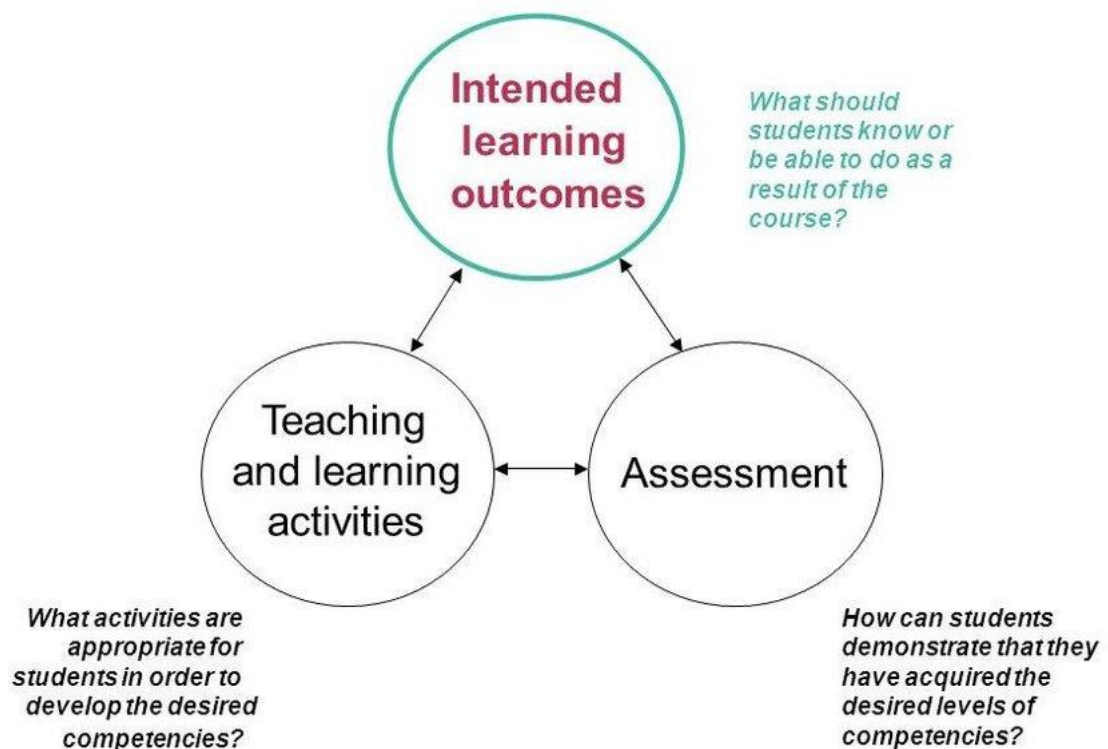
### **1.9 Learning theory underpinning simulation**

Simulation is often used to facilitate the acquisition of a new skill, to change a way of thinking within the learner, or to provide that learner with a greater depth of experience.<sup>(64)</sup> There are several overlapping theories which underpin simulation as a learning tool. By immersing the learner into the centre of the simulated scenario the participant is encouraged to experience active learning, as they actively have to participate in the process as well as reflect on their experience both during and after the simulation. Active learning within simulation is also an important element of the transformative learning process, whereby the learner brings prior knowledge and experiences to the simulated environment and is able to construct a new interpretation of how to perform a given task, or deal with a similar situation when it is encountered again in the future.<sup>(65)</sup> Transformative learning is the ultimate goal of any simulated learning experience, and if educationalists understand its role within the simulation process, the active learning experience of the participant can be improved. This is done by allowing the participant to immerse themselves in the simulation, reflect upon what they found challenging or uncomfortable within that experience, think about new ways of approaching a similar situation, and apply this new way of thinking in future encounters.<sup>(64)</sup>

It is important to recognise the role educational theory has to play with respect to the gap in knowledge identified within the literature. What has been demonstrated is a misalignment between what we expect our graduating students (and therefore FY1 doctors) to be able to do, and the realities of their capabilities when they begin their roles as doctors. The idea of aligning a curriculum was put forward by Biggs, who suggested that the intended learning outcomes of any curriculum must be aligned with the assessment regimen as well as the teaching and learning activities designed to deliver that curriculum.<sup>(66)</sup> Whilst we are not focusing on assessment per se, when a medical school assesses a student as competent to work as a doctor, that will undoubtedly include the competence to provide care to the dying, as expected by the GMC. It appears to be the failure to constructively align undergraduate curricula on care of the dying with reality and

expectations on the wards that appears to be leading to inadequate preparation of our students. The teaching methods we employ must engage learners in those activities that represent curriculum objectives, and one of the main issues with lecture based learning is the passivity imposed on students.<sup>(66)</sup>

The basis of constructive alignment is the constructivist theory of learning, which is an understanding that knowledge is constructed by learning through one's own activity,<sup>(67)</sup> rather than being told what to do by the teacher. It can be seen (Figure 1.3)<sup>(68)</sup> that this theory lends itself to simulated teaching as it has been explained that simulation creates an environment conducive to active and experiential learning, challenging the student to reflect on how they might act in a real-world setting.<sup>(69)</sup> Furthermore there are many elements within the constructivist theory that ring true for transformative learning,<sup>(64)</sup> and as such will warrant further exploration within later chapters of this thesis.

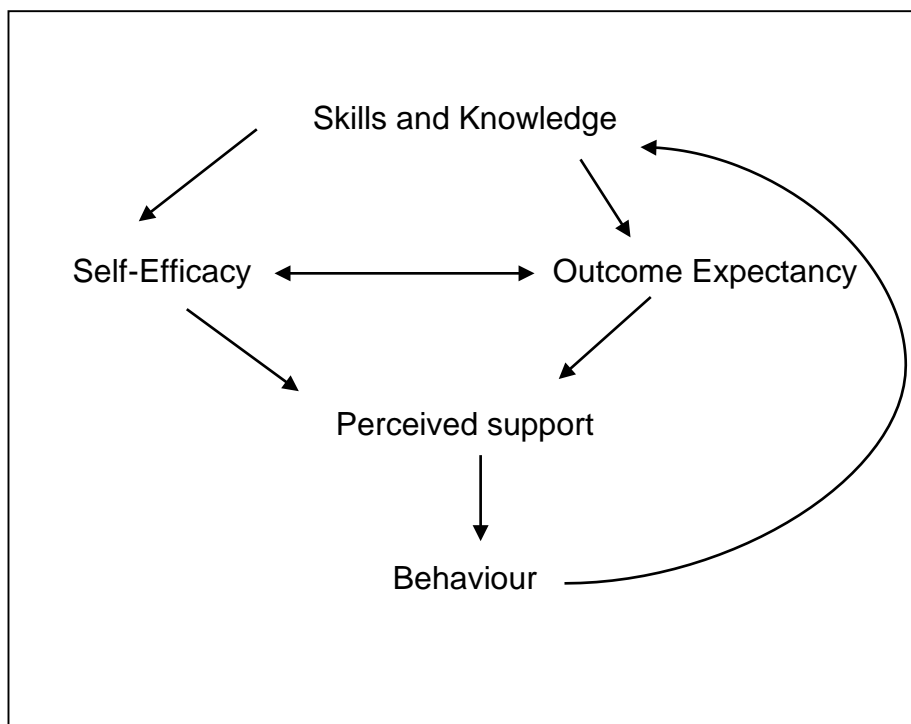


**Figure 1.3 Constructive alignment within a curriculum**

## 1.10 Theory of self-efficacy

This thesis explores whether simulation can improve the confidence and preparedness of medical students to care for dying patients. One question that arises from this is how can the improved confidence of a healthcare worker influence the care they give to a dying patient? The theory of self-efficacy put forward by Alfred Bandura in 1977 may help to answer this,<sup>(70)</sup> and Mason and Ellershaw (2008)<sup>(71)</sup> provide a summarised explanation of this alongside a diagrammatic interpretation (Figure 1.4):

“Self-efficacy theory illustrates the process of learning through which acquired knowledge and skills develop the targeted cognitive and behavioural objectives of clinical practice...appropriate training (knowledge acquisition) fosters confidence in one’s ability to meet objectives (Self-Efficacy) and illustrates the value of one’s actions (Outcome Expectancies), encouraging action (Behaviour/Clinical Practice)”<sup>(71)</sup> (p688)



**Figure 1.4 Theoretical model of efficacy and outcome expectancies on behaviour**

Self-efficacy is often dependent on the context within which it is being measured,<sup>(72)</sup> for example whilst one may feel confident to assess and manage pain in an otherwise well and communicative patient, they may feel less confident in managing pain in a patient who is dying and unconscious. A small but growing body of evidence suggests there is a positive link between improved self-efficacy and examination performance,<sup>(72)</sup> clinical performance as a whole,<sup>(73)</sup> and performance specifically in relation to palliative care skills.<sup>(74)</sup> Furthermore, the greater the perceived self-efficacy an individual has, the more likely they are to seek out more challenging activities and the better they are at managing their own stress and anxiety.<sup>(75)</sup>

Further work on the concept of confidence and self-efficacy helps to relate this theory in the context of complex clinical care. Bandura explained that given self efficacy is an individualised judgement of one's ability to successfully perform a behaviour required to produce a specific outcome (such as providing care for a dying patient and their family), if that same individual does not believe they have the necessary ability to perform a task then they are likely to avoid that task and avoid further difficult situations.<sup>(76, 77)</sup>

Bandura's theory of self-efficacy is not without criticism, with some early critics suggesting that the changes in ones' cognitive and behavioural processes cannot always be explained by changes in self-efficacy, without acknowledging the role a changing environment may have on these processes at an individual level.<sup>(78)</sup> In relation to clinical practice the self-efficacy of an individual to perform certain clinical tasks has been found to be affected by personal and environmental factors which may always act to limit the degree by which self-efficacy can be improved.<sup>(79)</sup>

The results of this study will be discussed in relation to Bandura's theory of self-efficacy, whilst recognising its limitations.

### **1.11 Summary**

Caring for dying patients is a reality for all doctors, irrespective of specialty. Doing so requires skill, patience and compassion, and as medical educators we have a responsibility to ensure that current and future generations of trainee doctors are given the opportunity to develop confidence in their ability to communicate with

and manage dying patients, as well as care for their families and others identified as important to the patient.

Dying is a diagnosis as important as any other, and there is now a significant body of evidence demonstrating that accurate and early recognition of dying leads to better outcomes for patients and their families. The five priorities of care enshrine the fundamental aspects of care that should be provided to every dying patient. When someone is dying there is a single opportunity in which to provide appropriate care for them, and as such these priorities are non-negotiable. Every doctor, new or experienced, should have the necessary skills to apply these care priorities to all their dying patients.

Despite welcome recommendations from several professional bodies for prioritising and improving palliative and end of life care training at undergraduate level, it remains evident that junior doctors, in the UK at least, feel unprepared and lacking in confidence when providing clinical, emotional and holistic support to the dying. The consequences are significant, from distress amongst junior doctors to negative impacts on dying patients and the families they leave behind.

Prior to the commencement of any study, an important next step will be to explore whether low confidence to care for a dying patient exists earlier in the educational trajectory, in particular at medical undergraduate level. Furthermore, it would be helpful to see how confidence is being measured, and identify what teaching interventions may be being implemented to address any observed low levels of confidence.

Given the evidence to support the use of simulation in the teaching of palliative medicine at postgraduate level, as well as the teaching of other specialties in undergraduate training, the next stage will involve an exploration of whether simulation could be applied in teaching medical students how to care for the dying. Whilst the earlier feasibility study <sup>(80)</sup> begins to answer this, there is an opportunity to build on this work and provide more robust evidence to support or oppose the adoption of such a teaching method within the palliative medicine curriculum.

This chapter has introduced the potential links that the theory of self-efficacy has with clinical performance, how simulation could be used to improve individual self-efficacy, and how this could be of value in teaching students how to care for dying

patients and their families with underpinning from the constructivist theory of learning.

## **1.12 Thesis aims and hypotheses**

### 1.12.1 Aims

The overarching aim of the work reported within this thesis is to ascertain whether simulation can be used to improve medical student confidence and preparedness to care for a dying patient and their family.

To help inform and support the main aim of this study there are a number of secondary aims:

- To better understand what is known about medical student confidence worldwide in caring for dying patients, identify how this is measured, and identify the nature and impact of any interventional teaching methods on student confidence to care for the dying, through systematic review of the literature.
- To use the outcomes of the systematic review to inform the choice of tool that will be used to measure confidence within our interventional study
- To gain an understanding of medical student attitudes towards the care of a dying patient and their family, and assess to what extent demographic variables exert any influence on these attitudes.

The primary and secondary aims listed above will be incorporated into three main areas of study, and will be referred to in the following way for the remainder of this thesis:

- Study 1: Systematic Review
- Study 2: What attitudes do medical students studying at Brighton and Sussex Medical School (BSMS) have with respect to caring for a dying patient and their family?
- Study 3: Does simulating the care of the dying patient have any effect on student confidence and preparedness?

### 1.12.2 Hypotheses

Hypothesis for study 2:

1. Student attitude towards caring for a dying person will be influenced by age, gender identity, year of study, and attainment of a previous degree.

Hypothesis for study 3:

- 1) Simulating the care of a dying patient and their family will affect the immediate and longer term confidence of medical students to provide such care.
- 2) Simulating the care of a dying patient and their family will affect the preparedness of medical students to provide such care.

## **Chapter 2: Medical student confidence to care for a dying patient and their family: a systematic review (Empirical Study 1)**

Part of this chapter has been published (Appendix A):

Wells G, Youssef E, Winter R, Wright J, Llewellyn C. Medical student confidence in care of the dying and their family: A systematic review. *BMJ Supportive & Palliative Care*. 2020 Jan

### **2.1 Introduction**

Across all training grades in the UK, Foundation Year 1 (FY1) doctors spend the most time with dying patients,<sup>(12)</sup> and realistically may find themselves looking after dying patients on their very first day.<sup>(19)</sup> In 2018 the General Medical Council (GMC) published updated guidelines for newly qualified doctors in its key document 'Outcomes for Graduates'. This document makes it clear that newly qualified doctors must be able to make appropriate clinical judgements when caring for patients at the end of life.<sup>(14)</sup>

In 2013 a survey of junior doctors demonstrated a lack of confidence and preparedness in general palliative care skills amongst FY1's, and of those surveyed almost two-thirds reported becoming distressed when caring for the dying.<sup>(15)</sup> This may not be surprising given findings that many FY1's report having experienced little or no exposure to dying patients at undergraduate level.<sup>(15)</sup> Contemporary research continues to demonstrate a lack of confidence amongst trainees in caring for dying patients who have lost consciousness.<sup>(81)</sup>

In 2013 a systematic review reported on the tools used to assess the effectiveness of undergraduate palliative care education, and found that there were no universally accepted validated questionnaires to measure this construct. The review demonstrated that there was much in the literature pertaining to changes in healthcare students' attitudes, skills and knowledge as a result of educational interventions, however it did not specifically seek to identify measurement of confidence in medical students in relation to the care of dying patients.<sup>(82)</sup>



Although some degree of overlap is acknowledged, the concepts of confidence and competence are recognised as separate entities within the literature. Whilst increased experience and clinical exposure correlates highly with students' confidence to perform certain tasks,<sup>(83)</sup> this increased confidence does not necessarily result in increased competence as measured by formal assessment.<sup>(84)</sup> Nonetheless, a perceived lack of confidence can have a negative impact on an individual's performance.<sup>(82)</sup> What is clear is that the relationship between confidence and competence is complex,<sup>(83)</sup> and whilst the literature suggests one can be confident to perform a task but not competent to do so, the reverse can also be argued.

Another important distinction to make is that which exists between the concepts of confidence and attitude. Again, whilst a degree of overlap may be present, the two concepts are often treated separately. Examples of this can be seen within undergraduate<sup>(85-87)</sup> and postgraduate<sup>(88, 89)</sup> literature. Furthermore, whilst confidence can be defined as the quality of being certain of one's abilities, attitude is defined as a feeling or opinion about something.<sup>(90)</sup>

In particular authors wished to look at whether students were confident at carrying out certain aspects of caring for a dying patient, from clinical assessment and prescribing skills, to communication with the patient and family.

By clarifying and defining such seemingly subjective terms, a degree of objectivity can be fostered which in turn will help authors clarify what it is they wish to investigate when formulating a research question. The aims of this systematic review were to identify literature pertaining to medical student confidence with respect to caring for a dying patient and their family, to critically appraise how confidence has been measured, and explore the impact of medical education interventions on confidence levels.

## **2.2 Method**

### **2.2.1 Protocol and registration**

This systematic review is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines<sup>(91)</sup> (Appendix B) and was registered with the International Prospective Register of Systematic

Reviews (PROSPERO) (Registration number: CRD42019119057) on 10th January 2019 (Appendix C).

### 2.2.2 Search strategy

In order to identify studies that reported measures of medical student confidence with respect to looking after dying patients and their families, a systematic electronic search using MEDLINE, CINAHL, EMBASE, ISI Web of Science, ERIC, PsychINFO, British Education Index and Cochrane Review databases was conducted on 15th October 2019 and again on 20<sup>th</sup> August 2020. Search terms used included permutations of the three main terms of medical student, confidence, and dying (Table 2.1), alongside appropriate database MeSH headings.

**Table 2.1 Systematic review search terms**

Main terms	Searched terms
Medical student	'Medic* adj3 undergrad*' 'Medic* adj3 student*'
Confidence	'confiden*' 'self-assur*' 'self-belief' 'self-esteem' 'attitude*' 'belief*'
Dying	'end of life' 'dying' 'death' 'palliat*' 'terminal*'

Permutations of the main terms were combined using the command 'OR'. The results for each main theme were then combined using the 'AND' command. This ensured that at least one permutation for each main theme was included in the title or abstract.

### 2.2.3 Eligibility criteria

Studies were included providing they met the eligibility criteria (Table 2.2). No restrictions were imposed in terms of publication year, country of origin, or study design as there was no rationale to do so. Peer reviewed articles were included alongside any other published works (abstracts, letters, editorials) provided they satisfied the eligibility criteria. Worldwide literature was included to facilitate a broader understanding of what is known about undergraduate confidence, allowing comparisons to be made with undergraduate curricula differing to that adopted in the UK.

**Table 2.2 Eligibility criteria**

<p><u>Inclusion Criteria</u></p> <p><i>Published works that included:</i></p> <ol style="list-style-type: none"><li>1. Medical students as study subjects</li><li>2. Measurement of confidence (via any methodology)</li><li>3. Care of dying patients (and not just palliative or end of life care in general)</li></ol> <p><u>Exclusion Criteria</u></p> <p><i>Published works that:</i></p> <ol style="list-style-type: none"><li>1. Were not written in English language</li><li>2. Referred to 'end of life' without specific reference to dying patients</li><li>3. Assessed attitudes without specific reference to confidence</li><li>4. Did not include adult patients</li></ol>
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#### 2.2.4 Study selection

All studies identified through database searches were exported into Excel for de-duplication. Remaining studies were tabulated and arranged alphabetically by author surname for more detailed review.

Due to the large number of studies identified, the primary reviewer (GW) excluded those that did not include all three inclusion criteria within the title and abstract alone. A second reviewer (RW) independently assessed 10% of these for eligibility (randomly selected studies).

Remaining eligible studies were retrieved using library services. Authors of unavailable studies were contacted to request an emailed copy, and were excluded if no reply was received. All successfully retrieved studies underwent independent full text review (GW and RW). Any disagreements regarding study eligibility were resolved by a third independent reviewer (CL).

A finalised list of all eligible studies appropriate for data extraction and quality assessment was created. Reference and citation searching of these was conducted to identify further eligible studies not found through database searching.

#### 2.2.5 Data extraction

Data extraction was undertaken independently by two reviewers (GW and EY). Data pertaining to study design, sample characteristics, significance of confidence levels and potential factors influencing confidence were extracted and tabulated onto an Excel data sheet. Data were checked for consistency and any discrepancies were resolved through discussion.

#### 2.2.6 Assessment of study quality

The methodological quality of each study was assessed by two independent reviewers (GW and EY) using the Mixed Methods Appraisal Tool (MMAT – version 2011).<sup>(92)</sup> The MMAT tool was designed to address the challenges faced when critically appraising qualitative, quantitative and mixed methods studies as part of a systematic review,<sup>(93)</sup> and as such was deemed an appropriate quality assessment tool to use for this systematic review given the methodological diversity found between the studies. Quality of studies can be scored as 0%, 25%, 50%, 75% or 100% depending on how many set criteria are met by the study

being assessed. Example criteria include whether there is a clear description of participant randomisation, participant response rate, and whether steps were taken to minimise bias within the study. Lower and higher percentage scores correspond to poorer and greater methodological rigour of each study respectively.

To evaluate the extent to which both reviewers agreed on study quality (inter-rater variability), a Cohen's kappa ( $\kappa$ ) score will be calculated for each eligible study. A score of  $\kappa=1$  would imply perfect agreement between reviewers, whilst a score of  $\kappa=0$  would imply no agreement.<sup>(94)</sup>

### 2.2.7 Outcome measures

Given the heterogeneity of data gathering tools used within the identified studies, a mixed-methods approach to data synthesis and reporting was adopted for this review. Data were extracted regarding details of the tools used to measure confidence along with their frequency of use amongst the studies.

For those studies reporting quantitative data, baseline mean confidence scores were extracted. Where studies reported an intervention had taken place, changes in the pre and post intervention confidence means were extracted and discussed.

For studies reporting qualitative data, descriptive analysis was undertaken to identify factors influencing confidence amongst medical students.

## 2.3 Results

Electronic database searches generated an initial 4301 studies at the time the first search was undertaken. After de-duplication ( $n=1582$ ), 2719 potentially relevant studies underwent title and abstract review. 2626 studies were excluded at this point leaving 93 for full text review. Reviewers (GW and RW) excluded 72 articles at this stage but were not able to reach a consensus on 9 articles. These underwent additional independent review (CL) who agreed that 3 should be included with the remaining 6 excluded. In total 78 articles were excluded leaving a final 15 articles eligible for inclusion into the review. Of note there were 3 articles where corresponding authors needed to be contacted in order to clarify queries regarding published data. Whilst only one author replied, all three articles were excluded from the study (Figure 2.1)

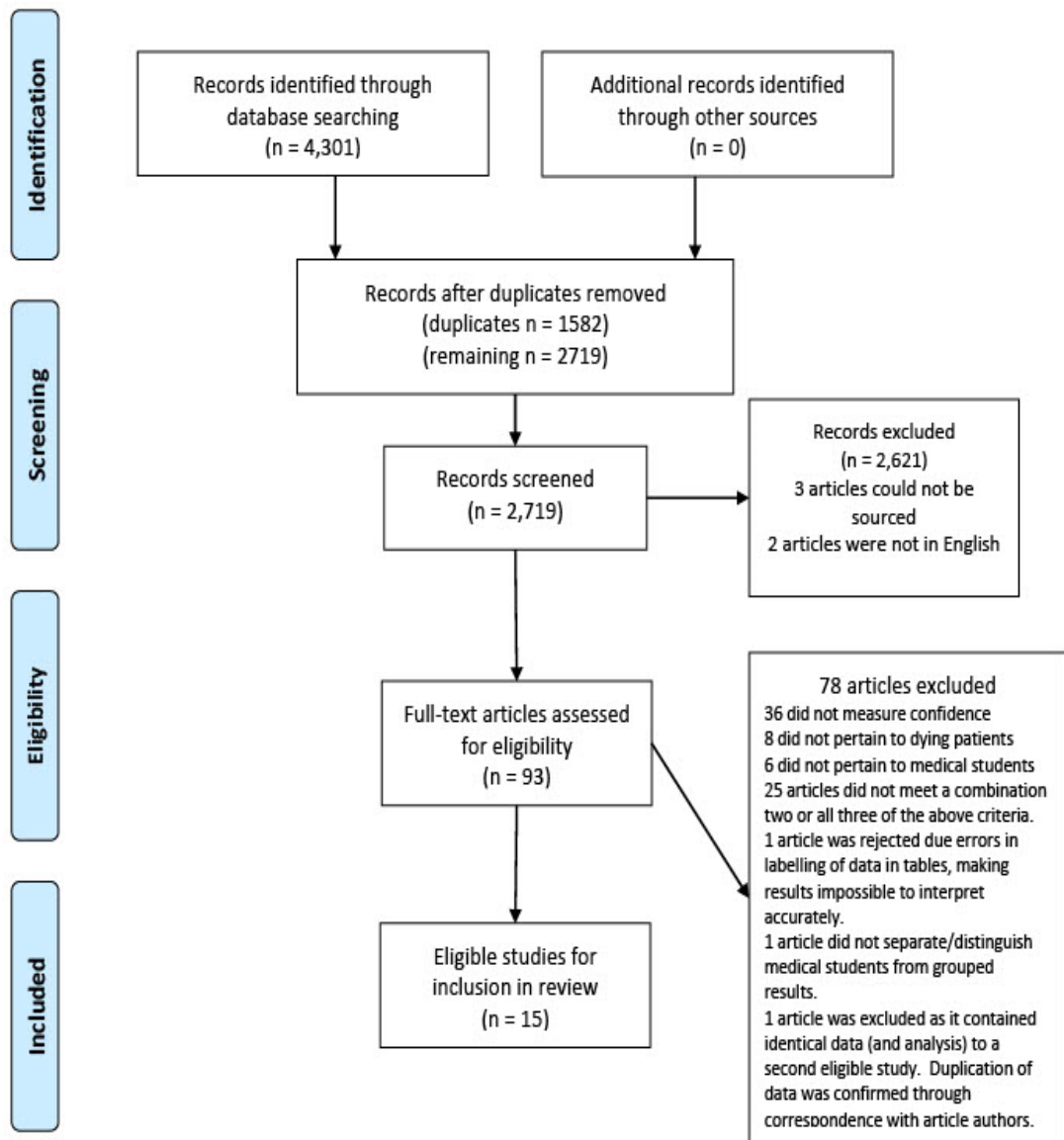


Figure 2.1 PRISMA flow chart

A second search was conducted to capture any further studies published since the date of the first search. This search was conducted in the same manner as before with the same search terms and databases used, but limited to include only those studies published between 2019 and 2020. A degree of overlap was accepted with the 2019 year to ensure there were no potentially eligible studies missed that may have been coming into print at the time of the initial search. This second search yielded a total of 334 eligible studies. Following removal of search duplicates (n=43), overlapping duplicates already reviewed as part of the original review (n=7), non-original research (n=16) and studies not written in English (n=1), a total of 267 studies remained. A further 261 studies were removed following title and abstract review, leaving a remaining 6 studies for full text review. Of these, one study was rejected as publication year was incorrect, having been identified as a 2020 study during the search it was in fact published in 2017 (and previously rejected). A further 3 studies were rejected as they did not perform measurements of confidence.

Overall two eligible studies<sup>(95, 96)</sup> were identified and included as result of the second search, details of which are presented in Table 2.3.

In total 17 studies were included within the review.

### 2.3.1 Study characteristics

Study characteristics are detailed in Table 2.3.

The majority of studies (n=5) were from the United Kingdom,<sup>(80, 96-99)</sup> with the remainder published in Germany (n=3),<sup>(74, 100, 101)</sup> Australia, (n=2)<sup>(102), (103)</sup> USA (n=2),<sup>(104, 105)</sup> India (n=1),<sup>(106)</sup> The Netherlands (n=1),<sup>(107)</sup> New Zealand (n=1),<sup>(108)</sup> and Denmark (n=1),<sup>(95)</sup> with a collaborative study between the UK and USA (n=1).<sup>(109)</sup> Publication year ranged from 1993 to 2020.

Study quality ranged from 25% (n=5) to 100% (n=2) with an average score of 53% across all seventeen studies. The majority of studies (n=13) lacked information regarding details of student selection and reasons for student non-participation, therefore discussions about selection bias were not particularly rigorous.

A Cohen's kappa score ( $\kappa$ ) of 0.63 was achieved following review of eligible studies from the initial search (October 2019), which suggests there was substantial agreement between both reviewers with respect to measurement of study quality.<sup>(94)</sup> The same independent reviewer was not available at the time of the second search (August 2020), but agreement was reached with regards to the MMAT score for both eligible studies identified in the second search between the primary researcher and a different independent reviewer (DK).

Of those studies using mixed-methodology (n=4), the qualitative aspect was represented by way of thematic/content analysis of student feedback,<sup>(80, 98, 103)</sup> or response to open-ended questions.<sup>(101)</sup> One further study was described as mixed-methods, however the qualitative aspect did not elaborate on any aspect of student confidence at all.<sup>(96)</sup> No study was solely qualitative in nature.

Ten studies included an interventional component, with pre and post-intervention measurements of confidence.<sup>(74, 80, 96, 97, 99, 101-105)</sup> These interventions included pairing students with an experienced clinician (n=2), participation in additional palliative care teaching tutorials and bedside learning (n=4), role play (n=3), and care of the dying simulation (n=1). One quasi-randomised controlled trial (RCT) was identified which involved comparing individual web-based interactive learning with small group teaching over a 2-month period.<sup>(104)</sup>



**Table 2.3 Characteristics of studies included in review**

Author, Year	Study design and questionnaire type	Country; Sample size; Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Barrington, 1999.	Quantitative prospective interventional pilot study with pre/post questionnaire (17-question Visual Analogue Scale (VAS) questionnaire)	Australia; n=20 5 <sup>th</sup> year students	-	12/20 (60%) students felt confident overall with aspects of palliative care, including care of the dying	Student matched with experienced nurse (preceptor) in a palliative care setting for three consecutive standard morning shifts	17/20 (83%) students felt confident overall with aspects of palliative care, including care of the dying  No statistical analysis reported	Supervised clinical experience positively affects confidence.  Acknowledged difficulty to interact with patients without first establishing rapport.  Clinical placements that provide such depth of experience are difficult to organise.	25%
Bharadwaj, 2007.	Quantitative prospective cross-sectional survey (Simple yes/no questionnaire)	India; n=111 Final year students	-	11/111 (10%) felt confident in managing symptoms of a dying patient.  32/111 (29%) felt comfortable talking about death to a dying patient.	-	-	'Arrogance ignorance paradox' resulting in observed higher level of confidence in undergraduates (compared to interns).  Recommends a case for improving palliative care training	25%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Brand, 2015	Prospective interventional study with mixed methods analysis - knowledge test, Self-Efficacy in Palliative Care (SEPC) questionnaire, and focus group. Validated for use in medical students	Australia; MCQ n=40 Survey n=28 Focus group n=6  2nd year of graduate entry programme	-	SEPC Visual analogue scale 0-100 (Not confident – confident) SEPC domains: Communication mean 25.77 (SD 12.20). Patient management mean 28.48 (SD 10.34). MDT working mean 31.65 (SD 10.28) Overall mean 85.98 (SD 25.81)	5-week oncology placement including 8 hours of palliative care lectures, ad hoc Problem Based Learning, and bedside tutorials.	Communication mean 40.07 (SD8.22), Pt management mean 39.16 (SD 7.71), MDT working mean 38.85 (SD 8.05). Overall mean 117.93 (SD 21.47) Paired T-test: Communication = -7.828 Pt management = -7.167 MDT working = -4.354. Overall = -8.1012-tailed sig = 0.000	Significant improvements in those areas pertaining to feelings of uneasiness and helplessness in caring for dying patients.  Potential reasons for low baseline confidence include lack of experiential learning, poor access to palliative care patients.	75%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Charlton, 1993	Quantitative prospective descriptive survey study.  11 item, 5 – point Likert questionnaire (0=no confidence, 5=very confident). Pilot tested	New Zealand;  n=392  Years 3-6 inclusive	Reports no differences between age, gender, ethnicity between year groups	Skill in counselling a distressed terminally ill patient (mean = 2.2)  Symptom control of a terminally ill patient: Nausea and vomiting (mean = 1.9);  Anxiety (mean =1.8); pain (mean = 2.1); constipation (mean = 1.9)	-	-	Increase in confidence as student's progress through undergraduate years.  Recommends students should encounter death from start of the course. Facilitate coping mechanisms via small group sessions. Follow up a dying patient. Breaking bad news seminars. Series of lectures involving pharmacologist, behavioural scientist, social worker, and spiritual advisor / chaplaincy.	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size; Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Day, 2015	Quantitative quasi-randomised controlled study  27-item Likert questionnaire (1=not confident, 5=very confident). Pilot tested	USA;  n=109  3 <sup>rd</sup> year students	57% female.  53% Caucasian, 19% Asian, Native American or Pacific Islander, 7% Black, 7% Hispanic	Recognising symptoms of imminent death: e-doctoring mode = 2. Small group mode = 2. Treating symptoms in a dying patient: e-doctoring mode = 2, small group mode = 2  Conducting family conferences around end of life care: e-doctoring mode = 2, small group mode = 1. Addressing family conflicts around end of life care: e-doctoring mode = 2, small group mode = 1	Quasi-Randomised controlled trial comparing web-based interactive education (e-doctoring) vs. small group education over a 2 month period	Recognising symptoms of imminent death:  e-doctoring mode = 3. Small group mode = 3. Treating symptoms in a dying patient: e-doctoring mode = 3, small group mode = 3. Conducting family conferences around end of life care: e-doctoring mode = 3, small group mode = 3 Addressing family conflicts around end of life care: e-doctoring mode = 3, small group mode = 3.  Student self-efficacy improved in both groups in all domains (p<0.001)	e-doctoring may standardise learning. Students felt e-doctoring may fit into schedules better.  Small group students reported better faculty contact and opportunity to practice.	100%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
De Witt Jansen, 2013	Quantitative cross-sectional survey using the 'Confidence in Treating Patients with Dementia in End-of-Life Care scale' (1-5 Likert scale, 1=strongly agree, 5=strongly disagree)	Northern Ireland & USA;  NI n=119  USA n=39  Final year students	NI = 59% Female, 99% aged 20-30, 87% White  USA = 74% Female, 90% aged 20-30, 79% Caucasian	NI students more confident than US students in managing pain at end of life and discussing effects of prescribed medications. US students more confident than NI students in implementing a palliative care system and answering questions about clinically assisted hydration and nutrition. Med students report low confidence in discussing spiritual aspects of death and dying, and eliciting goals of care (compared to nursing students)	-	No clear report of any statistical significance of differences in confidence between NI and US medical students	Increased clinical exposure to palliative care appears to positively influence confidence. Factors influencing confidence  1. Clinical experience working in palliative care can improve confidence in caring and communicating with dying patients and their families. 2. Receiving training and experience in breaking bad news can result in higher confidence in this task. 3. Increased experience and observing experienced colleagues can improve confidence in the psychosocial aspects of the dying process	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size; Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Gerlach, 2015	Quantitative prospective interventional study with pre/post questionnaire (1-4 Likert questionnaire, 1= rather not confident, 4 = confident. Adapted questionnaire developed by author from another study (Weber, Schmidl))	Germany; n=156 5 <sup>th</sup> year students	-	Accompaniment Pre-test results: 47(30%) unconfident, 82(53%) rather unconfident, 25(16%) rather confident, 2(1%) confident. Mean score = 1.88 (out of 1-4)	Seven 90-minute teaching sessions including communication skills, and live interviews with a palliative care nurse and bereaved relative	Accompaniment Post test results: 4(3%) unconfident, 66(42%) rather unconfident, 79(51%) rather confident, 6(4%) confident. Mean = 2.56 (1-4).  Overall confidence increased after the course. Median change in total score was 8 (p<0.0001). Overall improvement in score for 90(58%) of participants, with 57(37%) unchanged and 8(5%) impairment in score post intervention.	More longitudinal approach is desired. Study report suggest early integration of PC into undergraduate curricula. Longer study with evaluation of patient outcomes is necessary.	75%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Hawkins, 2015	Quantitative prospective interventional study with pre/post questionnaire (Evidence – based online questionnaire, 1-7 Likert scale)	UK;  Pre-intervention questionnaire n=37  Post-intervention questionnaire n=62  5 <sup>th</sup> year students	-	Recognising patients at the end of life; Mean confidence score = 3.4 (out of 7) Anticipatory prescribing; mean confidence score = 3.5 (out of 7).  Note paper reports an admin error was made, pre-intervention Likert scale was out of 7, whereas post-intervention scale was out of 5.	10-week student assistantship (5 weeks medicine, 5 weeks surgery)	Recognising patients at the end of life; mean confidence score = 3.8. (Out of 5 - relative increase of 28.6%) Anticipatory prescribing; mean confidence score = 3.6. (Out of 5 - relative increase of 25.0%).  No statistical analysis reported.	Students reported that improved confidence would come from more shadowing time than that recommended by the GMC.	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Healy, 2016	Quantitative prospective interventional study with pre/post questionnaire (The General Self-Efficacy Scale, a 1-4 Likert scale where 1= not at all true, 4= exactly true). Validated psychometric tool	USA; n=222 3 <sup>rd</sup> year students	49% Female 60% Caucasian, 19% Asian American, 17% Hispanic, 4% African American 90% aged 20-29	I am confident to teach a patient's family by the bedside about the last hours of life; Exactly true (ET) =6 (3%), moderately true (MT) =37 (17%), hardly true (HT) = 101 (45%), not true (NT) = 78 (35%).  I am confident to answer unexpected questions from family about the dying process. ET=7(3%), MT=51(23%), HT=102(46%), NT=61(28%)	The Double-Parallel Curriculum in Palliative Care. A case-based module entitled 'The Last Hours of Life', demonstration, and learner role-play using a bedside teaching tool	I am confident to teach a patient's family by the bedside about the last hours of life; ET=29(13%), MT=167(75%), HT=24(11%), NT=2(1%)  (p=<0.0001)  I am confident to answer unexpected questions from family about the dying process; ET=25(11%), MT=150(68%), HT=40(18%), NT=6(3%)  (p=<0.0001)	Argues the case for bedside teaching as a tool during curriculum activities. Learners reported statistically significant improvement in confidence levels in all areas after completing the curriculum programme.	50%



**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Mason, 2010	Quantitative prospective interventional study with pre/post SEPC questionnaire (Visual Analogue Scale).  Validated for use with medical students	UK;  Cohort 1 n=141  Cohort 2 n=308  4 <sup>th</sup> year students	Cohort 1 50% Female  Cohort 2 59% Female	Communication mean Cohort 1 = 34.31  Cohort 2 = 35.11  Patient Management mean  Cohort 1 = 32.49  Cohort 2 = 34.66  MDT working mean Cohort 1 = 45.02  Cohort 2 = 44.58	8-day educational programme (Cohort 1), involving clinical placement and PBL.  13-day educational programme (Cohort 2), involving clinical placement and PBL, advanced communications skills and ethics.	Communication mean Cohort 1 = 57.03 (p=0.000),  Cohort 2 = 67.89 (p=0.000)  Patient management mean  Cohort 1 = 60.34 (p=0.000)  Cohort 2 = 67.54 (p=0.000)  MDT working mean Cohort 1 = 65.08 (p=0.000)  Cohort 2 = 70.27 (p=0.000)	A diverse undergraduate education programme in palliative medicine leads to improved confidence in student's ability to meet the needs of dying patients which, according to Bandura's theory of self-efficacy, will result in improved patient care.	100%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Pieters, 2019	Quantitative questionnaire based on Weber et al (2011). 10-item questionnaire using 4 Likert responses of confident (C), rather confident (RC), rather non-confident (RNC), non-confident (NC). Pilot tested	Netherlands; 213 (222 asked but 9 did not complete data) Final year students	Mean age 24.9 (SD=1.79) 160 female (72.1%)	219 completed self-reported confidence.  Integrating psychological aspects of treating and supervising dying patients NC/RNC= 57.3%, RC/C=42.7%  Communicating with dying pts NC/RNC=38.5% , RC/C=61.5%  Treating and guiding dying patients NC/RNC=38.5% , RC/C=60.5%  Spiritual aspects of dying patients NC/RNC=77%, C/RC=23%	-	-	Lack of comms skills training in pall care programme may reflect the low confidence seen in communicating with patients at end of life.  Study found a positive correlation between self-confidence and knowledge (a better knowledge score was positively related to	25%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Rai, 2019	<p>Mixed-method multi-phase pilot study assessing the impact of PC undergraduate training by comparing two year groups using the IMEP-e tool</p> <p><b>International Medical Education in Palliative care electronic tool</b></p> <p>(Includes demographic data / SEPC / TS questionnaires)</p> <p>Year 3 – IMEPe questionnaire, year 5 – IMEPe questionnaire and focus groups.</p>	<p>UK; n=125</p> <p>Year 3 (n=95) were yet to receive PC training</p> <p>Year 5 (n=30) had already received PC training</p>	-	<p>Comm skills</p> <p>Y3: SEPC=23.51,</p> <p>Y5: SEPC=47.53 (p=0.001)</p> <p>Pt management</p> <p>Y3: SEPC = 28.71,</p> <p>Y5: SEPC = 54.98 (p=0.001)</p> <p>MDT working</p> <p>Y3: SEPC = 29.12</p> <p>Y5: SEPC = 54.01 (p=0.001)</p>	-	<p>Whilst there was an intervention of sorts (whether the students had received their undergraduate PC training), this was compared using two different year groups rather than the same year group pre and post teaching.</p> <p>Focus group data suggests students would value increased communication skills training in the form of simulated and ward based patients. There was a request for earlier exposure to dying patients.</p>	<p>A call for national data to provide important information regarding individual medical school training.</p> <p>Remainder of conclusions focussed on international application of IMEP-e</p>	25%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size; Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Weber, Braun, 2011	Mixed-methods prospective interventional study with pre/post questionnaire (developed by authors, 1-10 numerical rating scale 1=very low confidence, 10 = very high). Pilot tested.	Germany; n=163 4 <sup>th</sup> year students	71% Female  Median age 23 (21-36)	Confidence to interact with dying patients; median = 3, mode = 3	90-minute teaching module on a palliative care ward, supervised meeting with a patient with advanced cancer.	Confidence to interact with dying patients; median = 5.5, mode 4, 5 (p<0.001)	The significant improvement in self-assessed confidence in interacting with an incurably ill patient by meeting them in a secure surrounding is in accordance with positive effects reported in the context of patient-centred palliative courses.  Authors recommend the inclusion of a student-patient encounter as an essential and motivating part of a palliative care curriculum as being feasible despite a limited number of palliative care beds, time constraints of staff, and vulnerability of palliative care patients.	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Weber, Schmiedel 2011	Quantitative inter-institutional cross-sectional questionnaire based study (10-item questionnaire developed by an expert panel, using 4 Likert responses of confident (C), rather confident (RC), rather non-confident (RNC), non-confident (NC). Pilot tested	Germany; n=101 Final year students across 2 universities (76 Mainz university, 25 Gottingen university)	-	Addressing psychological aspects of severely ill and dying patients – C= 5(5%), RC =30(30%), RNC =52(51%), NC =17 (17%)  Addressing spiritual needs – C=5, RC=17, RNC=45, NC=33  Communication with dying patients – C=7, RC=36, RNC=40, NC=17  Treatment and accompaniment of dying patients – C=0, RC=20, RNC=51, NC=30	-	-	Final year German students are insufficiently prepared to care for terminally ill patients as self-assessed in their own level of confidence. Their strong vote in favour of a mandatory curriculum in pall care has gained recognition - legislative change was likely to take place at time of publication.	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Wells, 2019	Mixed methods interventional feasibility study.  Quantitative aspect used the Thanatophobia Scale to measure student attitudes, qualitative component used focus groups to ascertain confidence levels	UK;  n=6  4 <sup>th</sup> year medical students	Mean age 23.3 years  67% female	Pre and post measures of attitudes and not confidence per se.	Individual simulations involving the care of a dying person. Patient died in some scenarios, family member present (actor)	Focus group data demonstrated that some students felt a general lack of confidence going in to the simulations, and a lack of confidence to make clinical decisions regarding the dying patient.  Students keen to repeat simulations to further improve confidence. Repeat exposure	Lack of exposure to dying patients at undergraduate level.  Highlighted a lack of validated tools available to measure confidence.	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size: Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Melgaard, 2019	Cross-sectional study  15 item questionnaire-based survey.  Five-step scale from agree, somewhat agree, neither agree nor disagree, somewhat disagree, disagree	Denmark  n=250  5 <sup>th</sup> and 6 <sup>th</sup> year students	67.2% female  Age >25 years (61.6%)  Mean age = 26.1 (CI 25.9-26.3)	76.4% reported low confidence in managing treatment and support of dying patients.  54.8% reported low confidence in communicating with dying patients and their relatives	-	-	Implementation of an adequate palliative care curriculum has positive influences on outcomes.  Limited experience of palliative medicine negatively affects confidence levels.  Improvements in palliative care education in Danish med schools is required. Students request more palliative care education. They currently feel insufficiently prepared.	50%

**Table 2.3 (cont.)**

Author, Year	Study design and questionnaire type	Country; Sample size; Year of Study	Sample characteristics	Baseline confidence	Intervention	Post-intervention confidence, statistical significance of change	Factors influencing confidence / recommendations	MMAT score
Bansal, 2020	Mixed methods prospective interventional study.  Pre-post measures design with Likert style questionnaire. Free-text explanation of scores.	UK  n=83  Final year medical students	None reported	Providing care in the dying phase of illness:  15% not at all confident  36% a little confident  44% somewhat confident  5% quite confident  0% very confident	Role-play scenarios based on real life experience from authors' clinical practice.	Providing care in the dying phase of illness:  1% not at all confident  9% a little confident  42% somewhat confident  47% quite confident  1% felt very confident.  (p<.001)  Qualitative component did not specifically refer to care of the dying.	Pre-intervention confidence consistent with existing literature.  Small group role play can provide students with a safe place to practice skills and reflect on emotional responses to dying.  Confidence was lowest and improved the most for those domains where students had not had previous experience.  Students desire further 'real-life' practice. Concludes that further weight is added to importance of simulated practice and experiential learning.	25%



### 2.3.2 Participant characteristics

Medical student sample size ranged from 6 to 449 participants. Nine studies included data pertaining to student characteristics, however there was a lack of consistency between studies in terms of how characteristics were reported. With studies reporting gender identity characteristics (n=8), all reported a greater proportion of female participants (range 50% – 74%).<sup>(80, 95, 99, 101, 104, 105, 107, 109)</sup> Only six studies recorded participant age, with the commonest age range being 20 to 30 years old.<sup>(80, 95, 101, 105, 107, 109)</sup>

Ten studies included 5th/final year students.<sup>(74, 95-98, 100, 102, 106, 107, 109)</sup> One study reported on students within years 3-6 inclusive,<sup>(108)</sup> with the remaining six studies including either 2nd, 3rd, or 4th years.<sup>(80, 99, 101, 103-105)</sup>

Ethnicity was only reported in studies from the US (n=3), with Caucasian students representing the majority of participants.<sup>(104, 105, 109)</sup>

### 2.3.3 Measures of confidence

A variety of tools were used to measure student confidence. The majority of studies (n=10) used Likert style questionnaires, adopting 1-4 scale,<sup>(74, 100, 105, 107)</sup> 1-5 scale,<sup>(95, 96, 104, 108, 109)</sup> and 1-7 scale<sup>(97)</sup> variations. Visual analogue scales (VAS) were adopted by four studies,<sup>(98, 99, 102, 103)</sup> (of which three included the Self-Efficacy in Palliative Care scale). Two studies employed a 1-10 numerical rating scale,<sup>(101)</sup> and a simple yes/no questionnaire respectively.<sup>(106)</sup> The final study adopted a mixed methods approach, and whilst the quantitative aspect measured student attitudes, it was the thematic analysis of focus group data that specifically looked at confidence.<sup>(80)</sup>

Across all studies data reported how confident students felt across a variety of domains within the care of a dying patient. These specific domains are discussed below, in descending order of prevalence.

#### 2.3.3.1 Confidence in managing the physical symptoms of a dying patient

Twelve studies reported some measure of confidence in managing the common symptoms experienced by dying patients, such as pain, nausea, constipation and anxiety.

Baseline scores within eight studies demonstrated a general lack of confidence amongst medical students in the symptom management of the dying, with the majority of student scores falling into a 'not-confident' category, or with a mean result below 50% of the maximum achievable score. This was irrespective of which tool was used to gather the data, or whether it was an intervention study.<sup>(95-97, 99, 100, 102-104)</sup>

One medium sized study (n=125) measuring baseline confidence between third and fifth year undergraduates with respect to 'patient management' (which included symptom control) found that whilst third years were generally quite anxious with this domain, fifth years demonstrated greater confidence in comparison (p=0.001, large effect size).<sup>(98)</sup> These results echo those of a larger study<sup>(108)</sup> (sample size = 392) which compared confidence in symptom management of 3-6th year students. Using a Likert scale (0=low confidence, 5=high confidence) the study found that whilst confidence was low in year 3 (mean=0.6), it increased exponentially by year 6 (mean=2.9), without additional intervention and with a high degree of correlation.<sup>(108)</sup>

Interestingly the Dutch study<sup>(107)</sup> (n=213) found that the majority of students (60.5%) reported feeling confident in treating dying patients despite having an overall lack of confidence in providing palliative care in general. This shares some similarities with the UK/USA study which reported that UK students were more confident in managing pain in dying patients, including discussing the effects of medications, but less confident in discussing clinically assisted hydration (CAH) and nutrition (CAN) than their US counterparts.<sup>(109)</sup> This particular study gathered data using a 10-item Confidence in Treating Patients with Dementia in End-of-Life Care scale.<sup>(110)</sup> Whilst the study found that students with previous experience were more likely to feel confident discussing CAH and CAN (p≤0.01), those lacking experience were more confident in prescribing pain medications (p≤0.05). Effect size was not recorded.

### 2.3.3.2 Confidence in communicating and interacting with dying patients

Seven studies measured student confidence and comfort in communicating and interacting with dying patients, and results echo those for baseline confidence in managing physical symptoms. Six of the studies demonstrated a baseline confidence of less than 50% amongst students. One low quality study (MMAT

score = 25%) demonstrated that a small majority of students felt confident in answering a patient's questions about potential suffering or pain,<sup>(102)</sup> however this appeared to be an outlying result as the same study also reported that students had low confidence when speaking with dying patients about prognosis and lack of beneficial treatment options. No supporting statistical analysis was undertaken. Reporting within this domain were four intervention studies. Three of these studies demonstrated statistically significant improvements in confidence with communication when comparing pre and post-intervention scores ( $p < 0.001$ ). These interventions comprised of palliative care lectures, problem based learning and bedside tutorials,<sup>(103)</sup> a 90-minute ward-based palliative care teaching module,<sup>(101)</sup> and an 8 and 13-day palliative care educational programme.<sup>(99)</sup> A fourth interventional study also reported an increase in student confidence after attachment to a 'preceptor' (specialist palliative care nurse), however no statistical methods were applied to these results.<sup>(102)</sup>

Two moderate quality (MMAT score = 50-75%) German studies (one interventional<sup>(74)</sup>) measured student confidence in 'accompaniment' of a dying patient. Neither study defined accompaniment, however it was implied that this construct pertained to spending time with the patient, and both studies found students to have a baseline confidence of 17%<sup>(74)</sup> and 20%<sup>(100)</sup> in this domain. The interventional study demonstrated that 55% of students felt confident in accompanying a dying patient after attending a dedicated teaching course ( $p < 0.0001$ ).<sup>(74)</sup>

#### 2.3.3.3 Supporting families of dying patients

Five studies explored student confidence with supporting the families of dying patients.<sup>(80, 102, 104, 105, 109)</sup> One interventional study compared the effect of small group vs web-based interactive e-learning on student confidence, measured by a 24-item palliative and end-of-life self-efficacy scale.<sup>(104)</sup> Within the scale students were asked to rate their confidence with respect to conducting family conferences around end of life care discussions, dealing with angry family members, and managing family conflicts during end-of-life care (Scoring 1-4, not confident to very confident). Whilst pre-test scores were lower for the small group cohorts (mode = 1, not confident) compared to e-learning cohorts (mode = 2, a

little confident), both groups scored higher (moderately confident) on post-test scale application, although this was not statistically significant.

A second moderate quality (MMAT score = 50%) interventional study found that 81% of students lacked confidence in teaching family members about end-of-life care at the bedside, and 74% lacked confidence to answer questions from family members about the dying process. After the implementation of a specific end-of-life curriculum, reported lack of confidence decreased to a statistically significant 12% and 21% respectively. This was one of the larger sample-sized studies included within the review (n=222).<sup>(105)</sup>

A high quality (MMAT score = 100%) quasi-randomised controlled trial (n = 109) comparing small group learning with interactive web-based learning found statistically significant improvements in students' self-efficacy to manage certain aspects of family care, namely conducting family conferences and managing family conflicts with respect to dying patients. This improvement was found in both groups irrespective of teaching modality (p<0.001).<sup>(104)</sup>

#### 2.3.3.4 Addressing spiritual aspects of death and dying

Three non-interventional studies documented student confidence in addressing the spiritual needs of the dying. One study highlights the potential importance of spirituality in the dying process of individual patients,<sup>(100)</sup> quoting that undergraduate training interventions have, thus far, failed to show evidence of improvement in student knowledge of such issues.<sup>(100, 111)</sup> As a result the study justified focus on measuring student confidence in ability to address spiritual needs using a Likert-style questionnaire. Unsurprisingly 79% of students reported feeling non-confident in this area, and whilst no statistical analysis was performed, the study describes ability to address spirituality as being a major obstacle in undergraduate training.<sup>(100)</sup>

The second, joint UK-USA study utilised the Confidence in Treating Patients with Dementia in End-of-Life Care scale.<sup>(110)</sup> The study compared all participating medical students to a combined group of nursing students, summarising that medical students were less confident in discussing spiritual aspects of death and dying than the nursing students, though statistical significance of this was unclear.<sup>(109)</sup>

Whilst the third study described data pertaining to several aspects of confidence in caring for a dying patient, it was the integration of spiritual aspects of care that students appeared to find most challenging, with 77% of respondents (n=213) rating themselves as not-confident.<sup>(107)</sup>

#### 2.3.3.5 Provision of psychological support

Amongst other questions, one interventional study asked students to rate their confidence in providing hope and encouragement to patients and their families in relation to death, dying, and terminal illness. Pre and post-intervention confidence increased by 15%, with a borderline confidence level reported in the pre-intervention questionnaire (55% confident, 45% not confident). However, this was a low quality study (MMAT score = 25%) which lacked statistical analysis.<sup>(102)</sup>

The study comparing UK and USA medical and nursing students echoed the results seen regarding spirituality, with medical students being more likely to report low confidence in addressing psychosocial issues, although again no statistical analysis was offered. This study draws upon literature which reports that confidence can be improved with increased exposure and observation of experienced colleagues in managing psychological aspects of a dying patient's care.<sup>(109, 112)</sup>

One study specifically asked students to rate their confidence in integrating spiritual aspects when treating and guiding terminally ill and dying patients. It found this to be the lowest scoring domain, with just 23% of students (n=213) placing themselves in the 'confident' category.<sup>(107)</sup>

## 2.4 Discussion

This is the first study to highlight what is known about medical student confidence in relation to caring for a dying patient, identify how this has been measured, and describe the impact of teaching interventions employed by the studies in this review.

We found that amongst the studies in this review eleven different tools were used to measure confidence. Given such heterogeneity it is difficult to establish which were better at measuring the constructs of confidence or self-efficacy. However, some studies documented where their tools had been pilot tested for acceptability

(n=5),<sup>(95, 100, 101, 104, 108)</sup> internal consistency,<sup>(107)</sup> or validated as a psychometric test (n=4).<sup>(98, 99, 103, 105)</sup> Of note three studies utilise the SEPC questionnaire,<sup>(98, 99, 103)</sup> which is the only tool validated for use in medical undergraduates. As such it could be argued that this affords the SEPC a more robust foundation for its adoption in the measurement of student confidence in this setting.

All studies in this review found that medical students reported low confidence with respect to various aspects of caring for dying patients and their families. The majority of these studies involved some form of intervention with pre-post measures of confidence, and although statistical significance of results has not always been reported, it can be seen that the interventions have led to an increase in self-assessed confidence amongst student participants.

The main factors influencing observed low levels of confidence have been related to insufficiencies within undergraduate palliative care curricula at the time of publishing,<sup>(95, 107, 108)</sup> lack of compulsory curricula pertaining to care of the dying or palliative care in general,<sup>(100, 102)</sup> or failure to integrate care of the dying patient early enough into medical undergraduate training.<sup>(74)</sup>

There is a lack of clarity regarding the current organisation and funding of palliative care training within UK medical schools, with evidence of limited leadership and course review – factors which may well be contributing to the failure of some schools to adequately educate medical undergraduates.<sup>(113)</sup> The ability of graduating medical students to care for dying patients is considered a core competency,<sup>(14)</sup> and surveys demonstrate that the majority of medical students regard learning how to care for a dying patient as being of high importance.<sup>(114)</sup> Despite this, junior doctor confidence in managing dying patients appears to be mainly developed from exposure in postgraduate environments,<sup>(49)</sup> strengthening the argument that teaching on the care of the dying patient could benefit from earlier integration into undergraduate curricula.

This does not appear to be unique to the UK. In 2000 a survey of US medical schools demonstrated that 100% of undergraduate courses incorporated education pertaining to death and dying,<sup>(115)</sup> with 27% of schools offering a separate ‘death and dying’ course by 2005.<sup>(116)</sup> Despite this there remains no standardised undergraduate curricula to guide this teaching, which still takes the form of preclinical lectures.<sup>(115)</sup> Furthermore the number of hours dedicated to such teaching has remained unchanged since 2000.<sup>(116)</sup> The importance of

experiential learning in providing students with opportunities to put their skills into practice is emphasised, particularly in the context of the 'millennial medical student', who is typically seen to be practical in nature.<sup>(117)</sup> Over the 23-year publication period, the majority of studies conclude that continued lack of undergraduate experiential learning remains one of the key factors associated with the persistent reporting of under-confidence of undergraduates to care for the dying.

With respect to spirituality, the GMC and WHO recognise the importance spirituality has in promoting health and managing disease.<sup>(118)</sup> The concept of spirituality does not have to be a religious one, as many without religious beliefs will describe having an important spiritual component to their lives.<sup>(119)</sup> It can be described as a deep-seated sense of belonging, meaning and purpose in life.<sup>(120)</sup> Despite the GMC requirement of UK medical schools to incorporate teaching on spirituality at an undergraduate level,<sup>(14)</sup> current teaching practices remain unclear with a lack of standardised approaches.<sup>(118)</sup> In contrast, the percentage of US medical schools offering teaching on spirituality rose from 13% in 1994 to 75% by 2006 due to the recognition of its importance on patient wellbeing.<sup>(120)</sup> Just two studies<sup>(100, 109)</sup> (German, and joint US/UK studies) in this review specifically comment on confidence in addressing the spirituality of dying patients. One concluded that increased exposure to and observation of professionals addressing spirituality will help improve undergraduate confidence.<sup>(109)</sup> The second study did not draw any firm conclusions.

## **2.5 Limitations**

Given the low number of studies meeting the inclusion criteria, and heterogeneity of interventions it is difficult to ascertain which interventions appear most successful in improving student confidence. This is made all the more challenging given that statistical analysis of results was only undertaken in approximately 50% of studies, with the remaining studies either reporting that analysis was not likely to be meaningful due to lack of power, or simply not mentioned at all.

Studies included within this review span seven predominantly western countries. The geographical location of these studies is likely to have been influenced by the fact that in order to be deemed eligible, studies had to be reported in English. It is not inconceivable that relevant and important studies from other countries may have been excluded in this process, and as such this will severely limit the

generalisability of review findings to non-western countries. Inclusion (and translation) of research from non-western countries may afford opportunities to identify cultural differences with respect to talking openly about death and dying, and how this informs undergraduate curricula on care of the dying patient.

All studies reported some measure of baseline confidence. However, it was found that in the majority of studies, measurement of medical student confidence in caring for a dying patient and their family only formed a part of the overall outcome measures for each study. As such measurements were made by asking of single (or very few) questions within a larger questionnaire, or from combining the results of questions grouped together. There was heterogeneity with regards to those aspects of patient and family care against which confidence was being measured, with the majority focussing on physical symptomology (n=11), and communication skills (n=9).

A further important consideration relates to the nomenclature adopted between the studies with respect to the main concepts being reviewed. The use of broad search terms was necessary to ensure studies were not inappropriately excluded, with particular reference to the concepts of confidence and dying. It is clear that certain terms are subject to multiple interpretations, with 'end of life', 'actively dying', and 'terminally ill' being used interchangeably but with inconsistent definitions.<sup>(21)</sup> The same is true for the concepts of confidence, self-efficacy, and competence. Bandura<sup>(121)</sup> defines perceived self-efficacy as representing the confidence that one can use the skills necessary to cope with stress and meet situational demands. However, Bandura also states that perceived self-efficacy can be characterised as being competence-based,<sup>(121)</sup> a definition that is shared by other published authors.<sup>(122)</sup>

Such challenges within definitions can be seen outside of the medical literature. For example, one study offers clearer definitions between the two concepts, but argues that observed increases in confidence may arise from increased competence in the first place.<sup>(123)</sup> Further afield research highlights interweaved relationships between confidence and competence, recognising that as observers we feel uncomfortable if we perceive experts (be that a physician or car mechanic) to have low confidence – which may then cause us to question their competence.



A final limitation is in relation to the use of the MMAT. Reviewing authors (EY and GW) experienced some difficulties interpreting the tool guidelines when applying it to judge the eligible studies in this review. Both reviewers found some of the criteria overly complicated and difficult to follow, and on occasion poorly applicable to some of the more complex studies. This may in part explain why inter-rater reliability achieved a Cohen's kappa of  $\kappa=0.63$ , and whilst this suggests substantial agreement was reached, it also evidences a level of disagreement between both reviewers. Since the commencement of this systematic review it appears the content validity of the MMAT has been subject to in-depth review and subsequent revision based on findings that many other users have faced similar challenges in the application of this tool, with poorer level of agreement seen when applying it to qualitative and non-randomised studies.<sup>(124)</sup>

## **2.6 What this review adds**

This review has demonstrated a two-decade history of low confidence amongst medical undergraduates with respect to caring for a dying patient and their families, across a variety of countries. Measurements of confidence have been undertaken using a heterogeneity of validated and non-validated tools.

In the past decade increasing attention has been focused on the way medical students are taught to care for dying patients and their families, with governing body guidelines making clear the expectations of graduates in the care of one of the most vulnerable groups of patients. Despite this, junior doctors continue to report experiencing distress and a lack of confidence when caring for such patients in 21st century medicine.

As educators we must address the issues raised in the feedback we receive. It is clear that medical schools do not follow a standardised approach when it comes to teaching care of the dying, and where interventions are put in place it is unclear which ones achieve the best outcomes. This review has demonstrated that a lack of clinical exposure to dying patients and poorly structured palliative care curricula are repeatedly cited as being the main drivers perpetuating this ongoing feedback. It is hoped the results of this review will help support and guide critical appraisal of current teaching practices in learning to care for dying patients and their families.

In time this will facilitate the development of junior doctors with greater confidence to care for dying patients, paving the way for further study to demonstrate improved patient outcomes.

## **Chapter 3: Methodology**

### **3.1 Chapter outline**

This chapter describes the methods used in the design, execution and analysis of the two studies with primary data undertaken in the exploration of the research questions posed. Experience obtained by the primary researcher (GW) from an earlier feasibility study<sup>(80)</sup> has helped inform several stages of the design and development of both primary studies. Knowledge of previously observed limitations, feedback received from students and faculty, and experience from the peer review publication process has helped refine and shape the way both studies have been carried out. In addition, results from the systematic review have provided a rationale to support the choice of research questionnaire with which to assess changes in confidence in the undergraduate medical student population following an educational intervention.

### **3.2 Research questions**

The studies explored two distinct research questions, with additional sub-questions:

Study 2: What attitudes do medical students studying at Brighton and Sussex Medical School (BSMS) have with respect to caring for a dying person and their family?

Hypothesis: Student attitudes towards caring for a dying person will be influenced by age, gender identity, year of study and attainment of a previous degree.

Study 3: What effect does simulating the care of a dying patient have on student confidence and preparedness?

Hypotheses:

- 1) Simulating the care of a dying patient and their family will affect the immediate and longer term confidence of medical students to provide such care.
- 2) Simulating the care of a dying patient and their family will affect the preparedness of medical students to provide such care.

### **3.3 Reporting**

The methodological approaches to data collection differed between the two studies outlined above, and therefore separate reporting guidelines were followed based on the guidance from the Enhancing the Quality and Transparency of Health Research (Equator) Network.<sup>(125)</sup> The specific reporting guideline used for each section of the study is outlined below.

### **3.4 Empirical Study 2: Student attitudes towards caring for a dying person and their family**

#### **3.4.1 Study design**

A quantitative cross-sectional questionnaire study of medical student attitudes towards caring for a dying person was conducted.

#### **3.4.2 Reporting guideline**

This study is reported in line with The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement for cross-sectional studies (Appendix D).<sup>(126)</sup>

#### **3.4.3 Study setting**

Medical students in years 1-5 (inclusive) were approached at the three main teaching sites within the BSMS campus (University of Brighton campus, University of Sussex campus, Audrey Emerton Building (Kemptown)) between February and March 2019.

#### **3.4.4 Study population, sample size and recruitment**

The aim was to recruit a study population that was approximately representative of medical students in other UK medical schools. Therefore, a convenience sampling approach was taken, with the study survey open to any student studying in years 1-5 at BSMS.

#### **3.4.5 Eligibility criteria**

##### **3.4.5.1 Inclusion criteria:**

- Any student enrolled onto the 5-year BSMS undergraduate medicine course.

#### 3.4.5.2 Exclusion criteria:

- Any student who was intercalating or intermitting at the time of data collection

#### 3.4.6 Procedure

##### 3.4.6.1 Access to year 1-4 students

Faculty administrators were contacted to determine the times and locations at which all students would be together in their respective year groups for timetabled lectures. Once potential dates had been identified the corresponding lecturer was contacted to request permission to attend their lecture in order to explain the details of the study to the students, request their voluntary participation, and provide them with a paper questionnaire to be completed that day.

This process was continued until a mutually convenient lectures had been identified for all four year groups. In all cases lecturers agreed for the primary researcher to speak with students at the start of their lecture and distribute the questionnaire, before returning at the end of the lecture to collect completed questionnaires. There was no further follow up after collection of completed questionnaires for this part of the study.

##### 3.4.6.2 Access to year 5 students

During their final year at medical school, year 5 students are attached to clinical placements across several counties and are generally only together as an entire cohort during an exam period. However, throughout the year smaller proportions of year 5 students attend mandatory lectures as sub-groups. During the period of data collection approximately one third of 5<sup>th</sup> year students were present as a group, and this opportunity was used to approach this sub-group with details of the study and request their participation. In order to recruit students from the remaining two-thirds of the cohort, all remaining students were contacted via secure university email in order to provide study details alongside a request for them to complete the attached study questionnaire. This method of contact and data collection had been anticipated at the planning stage, and as such approval from the university ethics committee had already been granted. Those agreeing to participate were asked to complete the questionnaire and email it back to the primary researcher's university email address. To reduce the risk of breaching confidentiality, each student was emailed individually without the use of the

carbon copy function for sending multiple emails. All completed questionnaires returned were printed off and the individual emails to which they were attached deleted.

Each year group received a questionnaire (see 3.4.7) pre-labelled with their specific year of study. This was done to reduce the risk of questionnaires from different year groups being mixed together.

#### 3.4.7 Selection bias

To minimise bias the primary researcher endeavoured to address year 1-4 students in those lectures that were compulsory for entire year cohorts, rather than optional lectures which could attract a biased student demographic. Whilst it was unlikely that each lecture would have full cohort attendance, it was felt these lectures would yield the greatest response rate. After discussion with supervising colleagues, it was felt that following such an approach would be the best way of maintaining consistency and minimising selection bias. When addressing the students, it was explained that:

- 1) They were not to enter any personally identifiable information on the questionnaire in the interest of maintaining anonymity
- 2) Their consent was implied if they willingly completed it, and
- 3) Their participation was voluntary.

It was emphasised that there would be no effect on their grades if a student accepted or declined the invitation to participate, and students did not have to give a reason for non-participation.

For the year 5 cohort it is acknowledged that the method of data collection differs between those of the other years. Whilst all students in this year were contacted, there may be an element of bias in terms of the type of student that may have been willing to complete the questionnaire.

#### 3.4.8 Data collection: Study Attitudinal Questionnaire

An adapted version of the Thanatophobia Scale (TS) questionnaire<sup>(127)</sup> was used to collect data (Appendix E).

Thanatophobia is defined as a fear and associated anxiety in relation to death and the dying process, not necessarily of oneself but of others.<sup>(128, 129)</sup> The TS

questionnaire <sup>(127)</sup> contains seven statements designed to measure healthcare professionals' attitudes towards caring for a dying patient and their family. All seven statements pose a negative attitude towards caring for a dying patient and students are required to indicate to what degree they agree or disagree with each statement by assigning a score of between 1 (strongly disagree) to 7 (strongly agree). Once completed, a total score of between 7 (corresponding to a low degree of thanatophobia) to 49 (corresponding to a high degree of thanatophobia) can be achieved.

The TS questionnaire used in this study has been validated for use in medical students by Mason and Ellershaw (2004).<sup>(130)</sup> They found the original TS questionnaire was worded such that it was aimed at healthcare professionals rather than students in training, and as such some of the wording was considered to be less valid for medical students. During the validation process Mason and Ellershaw found that despite students being asked to 'imagine' how they might feel when deciding their score for each question, some students still felt unable to answer the questions, often citing their lack of clinical experience. Taking this into consideration (along with research ethics committee recommendations, see below) the questions were adapted to reflect a future tense with the aim of putting the questions into a context that was more relatable to undergraduate trainees. For example, where the original questionnaire stated:

“I feel pretty helpless when I have terminal patients on my ward”

The question was adapted to read:

“I would feel pretty helpless having terminal patients on my ward”

By making these adaptations it was hoped this would increase its validity and thus reduce the number of incomplete questionnaires returned.

One of the strengths of the TS questionnaire is that it takes less than 5 minutes to complete, and as such was felt to be the best available questionnaire with which to collect this data. Other questionnaires exist which measure attitudes towards providing end of life care, such as the Frommelt Attitude Toward the Care of the Dying Scale (FATCOD-B). This questionnaire consists of two sections, and formal validation has found that it is only the first section that is robust enough to

be used with medical students.<sup>(131)</sup> In addition, FATCOD-B consists of 30 questions and as such would take a much longer time to complete than the TS.

The Approach to Death and Dying Patients Attitude Scale (ADDPAS) has also been validated for use in medical undergraduates,<sup>(132)</sup> but as with the FATCOD-B it contains several items that would likely take in excess of several minutes to complete. In addition, there has been much less written in the literature with respect to application of this scale.

#### 3.4.8.1 Additional information requested

Additional information regarding student age, gender identity, and whether they had a previous degree was also requested. This data allowed a greater depth of analysis to take place in order to identify whether these variables had an effect on student attitudes.

#### 3.4.9 Data transfer

Once results were grouped by year of study each completed questionnaire was labelled numerically, for example 1.1, 1.2, where 1.1 would represent year one questionnaire one and so on. Doing this allowed data for each questionnaire to be easily cross-referenced after transfer onto an Excel spreadsheet, thus allowing each line of data to refer to individual paper questionnaires.

#### 3.4.10 Ethical considerations

Ethical approval was granted by the Brighton and Sussex Medical School Research, Governance and Ethics Committee (RGEC) to distribute the TS questionnaire to medical students at BSMS. RGEC agreed that if students voluntarily completed the TS questionnaire, it was not necessary for them to complete a separate consent form as well.

RGEC felt the wording of the questionnaire may be confusing, given that questions are phrased in the present tense to reflect answers from qualified clinicians. As described in 3.4.8 minor adaptations to word the questions in a future tense were thought to be sensible as this would enable students to convey how they currently feel about the thought of looking after a dying patient at a time in the future when they were qualified to do so.

All returned questionnaires were stored in a locked cupboard within a faculty research office. The office is located in a peripheral hospital trust building



accessible only to staff (both from the medical school and local hospital trust) who hold a valid identification (ID) card that has been granted specific access permissions. Access to the office is through two ID badge entry doors, and within the office itself the key to the locked cupboard was stored in a combination safe, the number to which is known only to research staff working in that specific office.

Email replies from year 5 students were accessed using a password-protected university laptop, via a secure (password-protected) university email account. All completed TS questionnaires received were printed and the emails to which they were attached were deleted.

#### 3.4.11 Statistical methods

Descriptive statistics were used to summarise both continuous and categorical data. Distributions of data were examined for normality with means and standard deviations reported for normally distributed variables, medians and interquartile ranges reported for non-normally distributed variables, and proportions and percentages reported for categorical variables.

Statistical modelling was used to analyse the relationship between the explanatory variables of year of study, age, gender identity, degree status, and the outcome variable of TS score. Following discussion with research supervisors and statisticians, multiple linear regression was the model chosen by which to undertake this analysis. This allowed for all variables to be entered into the model as it was felt they each had the potential to exert an effect on the dependent variable (TS score), and therefore should all be included into the model. As this study had a small set of explanatory variables, entry of data into the multiple linear regression model was done using the 'enter' method.<sup>(133)</sup>

All p-values are presented as 2-tailed, with significance defined as  $p < 0.05$ . 95% confidence intervals are provided for all parameters.

#### 3.4.12 Data coding

Year of study variable was treated as ordinal data, with data from years 2-5 compared to that of year 1. Gender identity and degree status variables were both treated as nominal categorical data. Student age was treated as continuous numerical data. Data coding was undertaken to facilitate statistical analysis (Table 3.1)

**Table 3.1 Coding applied to variable data**

<b>Variable</b>	<b>Code</b>
Year of study	Year 1 = 1 Year 2 = 2 Year 3 = 3 Year 4 = 4 Year 5 = 5
Gender identity	Male = 1 Female = 2 Other = 3
Degree status	No degree = 0 Degree = 1
Age	Treated as a continuous variable

#### 3.4.13 Missing data

For each TS questionnaire the total score was calculated as the sum of scores from all seven questions contained within it, with responders achieving a minimum score of 7 and a maximum of 49. For any missing data within the scoring section, discussion took place with the study team to ascertain whether these scores could be imputed using average scores within the remaining data. The decision whether to do this was dependent on the degree of missing data, and agreement was reached between the study team and faculty statistician that the amount of missing data was low enough to justify imputation of missing scores as described.

Missing demographic data was treated differently. As all questionnaires were pre-labelled with specific year of study prior to distribution, the TS score could still contribute to the results relating to the predictor variable of 'year of study' even if demographic data were found to be missing. Questionnaires with partially completed demographic data were still included in the analysis, but only to describe those variables for which data was present.

All data were analysed using IBM SPSS Statistics for Windows, Version 25.0<sup>(134)</sup>

### **3.5 Empirical Study 3: Does simulating the care of the dying patient have an effect on student confidence and preparedness?**

#### 3.5.1 Study design

For this study a simulated intervention with pre- and post-test measures was designed and conducted. Experience and outcomes from the prior feasibility study were used to guide the design of the intervention. In order to measure the constructs of student confidence and preparedness a mixed-methods approach was adopted. Quantitative data exploring student confidence was obtained using the Self-Efficacy in Palliative Care (SEPC) questionnaire (Appendix F)<sup>(102)</sup> at the pre, immediately post, and 6-months-post simulated intervention stages. Qualitative data exploring the advantages, disadvantages and realism (fidelity) of simulations, as well as student preparedness was obtained via post-simulation focus groups and subsequent thematic analysis (TA).

#### 3.5.2 Reporting guidelines

Study 3 involved a mixed methodological approach. The Equator network do not suggest any particular guideline for mixed-methodology studies in the area of medical education therefore the STROBE criteria for the quantitative component were followed as described for Study 2, and the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist<sup>(135)</sup> were followed for the qualitative component of this study (Appendix G).

#### 3.5.3 Educational Theory

It is important to recognise the role educational theory has to play with respect to the gap in knowledge identified within the introduction to this thesis, with a misalignment between what we expect our graduating students (and therefore FY1 doctors) to be able to do, and the realities of their capabilities when they begin their roles as doctors. In 1996 Biggs published his model of constructive alignment in which he suggests that the intended learning outcomes of any curriculum must be aligned with both the chosen assessment regimen and the teaching and learning activities designed to deliver that curriculum.<sup>(66)</sup> Whilst this study is not focusing on assessment, when a medical school assesses a student as competent to work as a doctor, that will include the competence to provide care to the dying as expected by the GMC. It could be a failure to constructively

align undergraduate curricula on care of the dying with reality and expectations on the wards that is leading to the inadequate preparation of our students. The teaching methods employed by universities (and medical schools) must engage learners in those activities that represent curriculum objectives. There is the potential for mainly lecture-based teaching to impose a certain degree of passivity on learners,<sup>(66)</sup> and this may begin to explain why some newly qualified doctors do not feel confident or prepared to care for a dying patient when the opportunity to impress the clinical context may have been missed during undergraduate teaching.

Underpinning constructive alignment is the constructivist theory of learning, which is an understanding that knowledge is constructed by learning through one's own activity,<sup>(67)</sup> rather than being told what to do by the teacher. When an individual begins to construct their own learning they often do so as part of a transformative learning process involving:

- An experience
- Self-reflection on performance, discomfort, and thoughts resulting from the experience
- Developing new ways of thinking and learning
- Repeating the experience whilst implementing this learning by way of a new approach<sup>(64, 65)</sup>

This theory lends itself to simulated teaching as such simulation creates an environment conducive to active and experiential learning, challenging the student to reflect on how they might act in a real-world setting.<sup>(69)</sup> The findings of this study will be discussed within the context of the constructivist theory of learning for both quantitative and qualitative results, with any change in confidence seen being viewed with a constructivist lens. Themes identified from focus group data that support or refute the concept of constructive alignment in the context of student experiences of undergraduate teaching on care of the dying will be explored.

#### 3.5.4 Study population

A convenience sample of students from the 4<sup>th</sup> year undergraduate medicine cohort at BSMS was chosen for this study. The 4<sup>th</sup> year group was felt to be the most appropriate because:

- Students in this year would have already experienced one full academic year involving clinical placement and exposure to patients.
- The 4<sup>th</sup> year timetable allowed sufficient flexibility in order to conduct the simulations without requiring students to be away from clinical placements
- The 4<sup>th</sup> year of study at BSMS includes a rotation in palliative medicine

### 3.5.5 Eligibility criteria

#### 3.5.5.1 Inclusion criteria:

- Any medical student currently enrolled in the year 4 cohort at BSMS

#### 3.5.5.2 Exclusion criteria:

- Any medical student who was undertaking a period of intercalation or intermission
- Any student who felt their participation would cause them distress in relation to any personal or emotional factors, e.g. a recent bereavement
- Any student who did not complete a consent form
- Any student who did not complete the pre-simulation Self Efficacy in Palliative Care (SEPC) questionnaire.

### 3.5.6 Sample size

This study was conducted with a sample size of 40 students, a figure which was determined by several logistical factors described below. Ideally the sample size would have been based on data from previously conducted studies, however following scholarly review such data had not been identified by the time the logistical aspects of the study were arranged.

At the time simulations were being conducted (March-May 2019), the systematic review was being completed ready for publication. During this process a paper published in 2014 came to light which detailed the use of the SEPC as part of a pre-post intervention study, with changes in mean SEPC scores and associated standard deviations.<sup>(136)</sup>

These data allowed a retrospective sample size calculation to be conducted to ascertain whether this simulation study had been adequately powered to detect a statistically significant difference in mean SEPC score. Whilst this approach was far from ideal, details of this calculation are described below, and limitations of this approach will be discussed later in the thesis.

#### 3.5.6.1 Logistical considerations

Student availability, simulation suite availability, and simulation timings were all factors which had to be considered in combination as these would ultimately dictate the maximum feasible sample size we could accommodate.

#### 3.5.6.2 Student availability

Dates within the timetable where students were allocated 'free study' time were identified. Timetabled free study always occurred between normal working hours (09:00 – 17:00) and there were no expectations for students to attend particular lectures. Instead students were required to use this time to undertake independent study as individuals saw fit. Several free study periods were identified and these were all dates on which the simulations could potentially take place.

#### 3.5.6.3 Simulation suite availability

There are multiple simulation suites available at BSMS. These are highly coveted learning resources, and as such their availability is at a premium. To maintain consistency, it was important to use the same suite for all simulations. It was felt that the Watson building suite situated on the University of Brighton Falmer campus would be the most appropriate as it was the suite that was most familiar to the students. The suite consists of a simulation room, control room, and adjacent observation room (which is often occupied independently of the suite as a teaching room in its own right). In order for students to observe each simulation, it was necessary to have the entire suite available for the study.

Liaison with simulation suite administrative staff at the beginning of the academic year identified those dates where the entire suite was available. Available dates were cross-referenced with the year 4 free study days, and this led to the identification of four full days upon which both the students and the suite would be available to enable the simulations to run. It was essential to book these four dates well in advance of the study to ensure they remained available for the time that the simulations would be conducted.

#### 3.5.6.4 Simulation timing

Based on experience from the feasibility study, timings for all aspects of the simulations were mapped out (Appendix H). Taking into account an introductory session, individual simulations, debrief sessions, focus groups and appropriate

breaks for refreshments, it was ascertained that each half day could realistically accommodate 5 simulations, which could be repeated in the second half of the day for a separate group of students. It was therefore feasible to accommodate a total of 40 separate simulations across the four identified dates.

### 3.5.7 Retrospective sample size calculation

In 2014, Sweeney *et al* <sup>(136)</sup> published data pertaining to a study assessing the educational impact of a palliative care teaching module on students' perceived knowledge and skills. They distributed the SEPC questionnaire to a mix of second-year (graduate entry) and third-year (direct entry) medical students (n=24) both pre and post module to identify whether their perceived knowledge and skills had been influenced by the teaching module. Paired t-tests had been used to calculate pre and post-module mean SEPC scores (and standard deviations) for all three sub-categories of patient communication, patient management, and multidisciplinary team work.

From this data it was possible to calculate the effect size achieved for all three sections of the SEPC, which itself facilitated the calculation of the post hoc power achieved by their study (Table 3.2).

**Table 3.2 Effect size and achieved power of study published by Sweeney et al (2014)**

SEPC domain	Sample size	Mean Pre – module	SD Pre – module	Mean Post - module	SD Post module	Effect size (dz)	Achieved power (1- $\beta$ err prob)
Communication	24	35.0	16.4	62.8	14.7	1.78	1.00
Patient Management	24	44.9	14.3	65.3	15.2	1.38	0.99
Team Work	24	55.8	20.0	67.4	12.3	0.67	0.88

Data from this study enabled a post-hoc sample size calculation to be undertaken to determine what minimum number of students would have been required to achieve a study with a minimum power of 0.8, an alpha of 0.05 (Table 3.3)

**Table 3.3 Sample size calculations for increasing power**

<b>SEPC domain</b>	<b>Effect size</b>	<b><math>\alpha</math> error probability</b>	<b>Power</b>	<b>Sample size required</b>
<b>Communication</b>	1.78	0.05	0.8	5
<b>Patient Management</b>	1.38	0.05	0.8	7
<b>Team Work</b>	0.67	0.05	0.8	20
<b>Communication</b>	1.78	0.05	0.95	7
<b>Patient Management</b>	1.38	0.05	0.95	9
<b>Team Work</b>	0.67	0.05	0.95	31

This data suggests that a minimum sample size of 31 would be adequate to undertake a 95% powered study to detect moderate-to-large effects between pre- and post-study measures of confidence using the SEPC questionnaire.

Although our simulation study was completed without a sample size calculation, this demonstrates that the sample size of 40 would fulfil the requirements for a study that was adequately powered to detect a difference, whilst allowing for a degree of student attrition.

All measurements of power, sample size, and effect size were calculated using G\*Power (version 3.1.9.4).

### 3.5.8 Recruitment procedure

In February 2019 the 4<sup>th</sup> year cohort was addressed by the primary researcher in order to explain the nature of this study. In a similar manner to study 2, a compulsory lecture was identified where it was anticipated that all 4<sup>th</sup> year students would attend. Permission was sought from the appropriate lecturer to allow the primary researcher to talk about the study. Students were informed that they would be contacted in a randomly-allocated order by way of a follow-up email with a request for their participation in the simulation study. It was explained that this email would contain details of the dates, times and location the simulations



would be taking place. Students were informed that their decision whether or not to participate would not affect their training in any way.

#### 3.5.9 Randomisation of students

This was achieved by entering the names of all students enrolled onto the 4<sup>th</sup> year BSMS undergraduate medicine course at the start of the 2018 academic year onto an Excel spreadsheet in alphabetical order. Each name was assigned a random number via the application of the RAND function in Excel. These numbers (with attached names) were then ordered from lowest to highest, thus creating a randomised contact list of students.

#### 3.5.10 Simulation date allocation

The first 40 students on the list were contacted via university email with a request for their voluntary participation. Students were asked to reply within 7 days from receipt of the email, clarifying whether they wished to accept or decline the invitation. Those that declined were not required to give a specific reason for doing so, and were not contacted any further. Those who did not reply to the initial email were contacted a second time with the same invitation to participate and a request for a response within 7 days. Individuals failing to reply to this second email were recorded on the spreadsheet as 'no reply' and were not contacted any further. Two weeks after the first 40 students had been contacted, the number of accepted and declined/non-respondent invitations were tallied. The remaining places available within the study were then calculated, after which an identical number of students next in line on the list were invited to participate. This process continued until all 40 places were filled.

Students expressing an interest were asked to confirm which simulation sessions they preferred to attend. There was no opportunity to add further simulation dates and times beyond the eight sessions that had already been arranged, therefore where students were able to attend more than one date, the earliest was chosen in preference. Adopting this approach meant that the earliest simulation dates could be filled first, therefore reducing the chance of earlier simulations being under filled and resulting in a lower total student number.

Student students were sent the SEPC questionnaire through a secure university email account prior to arriving to their allocated simulation day. It was a requirement that each student completed their questionnaire before they took

part in the simulations, and as such were asked to bring their completed questionnaire with them on their chosen day.

### 3.5.11 Participation incentive

There was no financial incentive offered to students, instead it was explained to the year 4 cohort that if the research was able to go ahead, and providing the sample size of 40 students was reached, the primary researcher would offer to run a focussed revision session in advance of their fourth-year summative assessments to cover some common topics within medicine, palliative medicine, general practice, and pharmacology. This was open to all fourth-year students including those who did not participate in the study.

## 3.6 Study simulations: the intervention

### 3.6.1.1 Pre-simulation preparation

The study took place in the simulation suite located in the Watson Building, BSMS, Falmer Campus. For all eight simulations there was a facilitating faculty group that consisted of:

- The primary researcher
- A consultant in palliative medicine affiliated to BSMS
- A trained simulated-mannequin operator
- A professional actor

Each simulation took place on a Friday, and all participating faculty members were contacted at least 1 week in advance to ensure they were prepared for the day, providing them with an opportunity to clarify any specific queries. Actors were sent fully prepared scripts several weeks in advance (Appendix I), and the simulated-mannequin operator was sent details of the parameters that were required of the mannequin for each scenario (Appendix I). A 20-minute Microsoft PowerPoint presentation on symptom control in the dying patient was prepared by the primary researcher and reviewed by the primary palliative medicine consultant facilitator (AH), to agree on its content. To maintain consistency, the final edited presentation remained unaltered for the duration of the simulation study to ensure that all students were presented with the same information irrespective of which simulation group they were in.

Prior to students arriving, the simulation suite was set up in preparation for the day ahead. All prepared documentation (mock patient notes and drug charts), 20-

minute presentation, scenario scripts, mannequin settings, audio-visual equipment (allowing closed-loop communication between the facilitator and the actor), and simulation room environment were prepared in advance.

#### 3.6.1.2 Simulation day running order

Students attended their allocated simulations in groups of five, with each group attending for half a day (4-hours) in total. This meant two groups (10 students) could participate in each of the 4 simulation days. Students were asked to arrive on time in the simulation suite observation room. At the start of each session pre-simulation SEPC questionnaires and consent forms were collected by the primary researcher. Any students who arrived without either of these documents were provided with blank copies and were required to complete them prior to the start of the introductory session. Following group introductions, the logistics for the half-day session were explained. Students were asked to pick a number out of a container (folded pieces of paper numbered 1 to 5) to determine the order in which they were to participate.

The Consultant facilitating on the day (AH, OM or DB) presented the PowerPoint presentation to the students using a large touch-screen monitor. This was followed by a short presentation from the primary researcher during which students were provided with details of the simulated patient and associated medical history. For all scenarios the patient and underlying diagnosis remained the same, but with differences between the tasks to be carried out by the student. In each case the patient was a 58-year old gentleman with a diagnosis of metastatic lung cancer.

Each scenario (Appendix I) was read out to the participating group prior to starting individual simulations. Each student was given further time in the corridor between the observation and simulation rooms to re-read the scenario and prepare themselves.

During this time the primary researcher checked that both the simulation mannequin operator and the actor were ready for the scenario to begin. The primary researcher spoke to the actor through the use of a headset as this allowed minor adaptations to be made if it was felt the student was leading the simulation in a direction that was not appropriate, and allowed an element of flexibility by guiding the actor if the student became stuck or distressed.

In each simulation the scenario ended either:

- When the scenario had reached 8 minutes' duration
- The student felt they had achieved what they could and had begun to end the scenario themselves (usually thanking the relative and starting to leave the simulation room)

Each simulation was followed by a 5-minute debrief in the observation room, where all observers, students and facilitators were able to provide constructive feedback.

On all simulation days, a 25-minute refreshment break was provided between the second and third simulations. Once all five simulations and associated debrief sessions had been completed, a further 5-minute comfort break was provided prior to starting the focus group. All focus groups were conducted in the observation room over a 30-minute period.

### 3.6.2 Faculty involvement

Given the emotive and intense nature of the simulations and subject matter, both the research team and RGEC felt it would be important for a senior member of the palliative care team to be present both to offer the pre-simulation teaching and to be available to provide support in the event that any student became distressed. As a result, a palliative care consultant was present for all simulations as well as the primary researcher.

The smooth running of each simulation was facilitated by monitoring the progress of each scenario, observing timing, communicating with other members of the facilitating group, and running both the inter-simulation feedback sessions and post-simulation focus groups. The facilitating consultant remained present in the observation room with the remaining students as each simulation was in progress. Any observing student who became distressed could then be supported by the consultant whilst allowing the simulations to continue.

Given the intense nature of the simulations, two different actors were hired to play the role of the simulated patient's relative. Each actor attended for half-a day, with a different actor for the morning and afternoon sessions. The research team hired actors through an established company used regularly by BSMS to help with the

running of formal medical student examinations. These actors were already experienced in providing constructive feedback to medical students, and had been trained to deal with the highly emotive content of the simulated scenarios.

It was not possible for the same consultant to be present for all eight simulations due to clinical commitments, therefore three different consultants volunteered their time to help cover the eight sessions. All three were affiliated with BSMS and had been involved in undergraduate and/or postgraduate training.

The simulated-mannequin operator was not required to engage with the students and was present to operate the mannequin as scenarios dictated. With the exception of the faculty, there were no other non-participating individuals present for any of the simulations.

### **3.7 Qualitative data collection**

#### **3.7.1 Focus groups**

Each focus group consisted of five students. Questions were semi-structured and based on topic guides which had been refined following pilot testing as part of the earlier feasibility study. In particular, we wanted to look for what impact, if any, the simulations may have had with regards to their preparedness to care for dying patients.

#### **3.7.2 Focus group topic guide**

Topic guides were developed through discussion with the study team in order to provide a framework for the focus groups (Appendix J). Focus group guides should act as prompts rather than direct questions, with participants free to agree and disagree with one another in the interest of developing dynamic and thought-provoking discussion.<sup>(137)</sup>

Students were asked to describe how they felt following their simulations, whether they found the simulations to be a realistic representation of their experience in clinical practice. It was also important to find out whether students felt the current level of teaching and experience at BSMS prepared them to look after dying patients and their families.

#### **3.7.3 Procedure**

There was a single focus group conducted for each group of five students, with no student participating twice. However, in order to maintain consistency each

focus group was run in the same room with the same facilitator (GW) on every occasion. Questions were asked in the order set out in the topic guide, with interruptions by the facilitator kept to a minimum, and only occurring in order to seek clarification of student responses or to encourage quieter members of the group to participate.

All focus groups were recorded using two separate Dictaphones (direct to audio file) placed in separate locations within the room. This was done to:

- Reduce the risk of non-recording of focus group data due to Dictaphone failure
- Provide the facilitator with two separate recordings from which data could be extracted, thus increasing the opportunity to hear quieter voices or difficult sentences.

In order to maintain the available timeframe for each simulation session, 30 minutes were allocated for each focus group.

#### 3.7.3.1 Field notes

During each focus group the facilitator kept a running log of each student's responses, recording initials and times each person spoke. This was done to facilitate a more accurate transcription of Dictaphone recordings, especially at times when individual voices may be difficult to distinguish. In order to facilitate anonymity, initials of each student were re-designated as an individual alphabetical letter during the transcription process.

#### 3.7.3.2 Transcripts

Focus group recordings were uploaded and saved onto a password protected laptop and labelled ready for transcription in date order. Data was transcribed as soon as possible after each focus group was completed so as to minimise the risk of omissions and errors occurring within the transcripts. Recordings were played using Windows Media Player which allowed recordings to be slowed down, paused, and rewound in order to facilitate verbatim transcription onto a Microsoft Word document. Field notes were cross referenced to facilitate the designation of assigned alphabetical letters to individuals' paragraphs and sentences. Once the data was transcribed, the primary researcher listened through the focus group recordings again a second time to identify any errors or omissions in the transcripts, and also took this opportunity to identify some of the

more significant paralinguistic features within the data as set out by Braun and Clarke in their adaptation of a transcriptional notation system for orthographic transcription.<sup>(137)</sup>

Due to anonymisation, and the fact that each focus group contained multiple students, transcripts were not returned to individuals for review. All transcriptions were carried out by the primary researcher.

#### 3.7.4 Analysis

Thematic analysis (TA) is a term used to describe a variety of different approaches to qualitative data analysis, with different versions underpinned by different philosophical and conceptual frameworks. Braun and Clarke (2006) have described it as a foundation method for qualitative analysis, arguing that it should be the first method adopted by researchers when analysing qualitative data,<sup>(138)</sup> as the researcher who is unfamiliar with qualitative methodology will find TA easy to grasp and quick to learn.<sup>(139)</sup> The main point of TA is to identify, analyse and report patterns and themes within qualitative data, often providing a rich description of your dataset.<sup>(138)</sup> Unlike conversational analysis, interpretative phenomenological analysis, grounded theory and discourse analysis, all of which are dependent on an underlying theory or epistemological approach, TA can be applied across a range of theoretical and epistemological approaches.<sup>(138, 139)</sup> TA is also considered an appropriate tool for examining the perspectives of different research participants.

TA of transcripts was carried out following the methodology set out in Braun and Clarke's 6-step guide:<sup>(138)</sup>

1. Familiarisation with the data through transcription, reading and re-reading data
2. Generating initial codes of interesting features in a systematic fashion across the full data set
3. Searching for themes through collation of codes
4. Generation of a thematic map to check if themes work in relation to coded extracts and the full data set
5. Defining and naming the themes, refining specifics within each theme with clear definitions

6. Report production, opportunity for final analysis. Selection of particularly vivid or relevant extracts which demonstrate a clear relationship to the research question and literature findings.

Experience gained by the primary researcher from undertaking TA as part of the feasibility study lends itself to undertaking a deductive approach to TA as part of this study. This is where coding and theme development are directed by existing concepts and ideas and is driven by a researcher's theoretical and analytical interests rather than purely by the content of the data itself. <sup>(139)</sup> As such it will lend itself to interpretation of the results within the context of constructive alignment and the theory of self-efficacy, both of which are important underpinning elements of this study. Transcripts were imported into NVIVO 12 software which facilitated creation of initial codes, nodes, themes and sub-themes.

### **3.8 Quantitative data collection**

#### **3.8.1 Study self-efficacy questionnaire**

Quantitative data was collected using the Self-Efficacy in Palliative Care (SEPC) questionnaire. This was originally developed for use with undergraduate medical students to assess the effectiveness of experiential learning in palliative care, <sup>(102)</sup> and was generally used for descriptive purposes. <sup>(130)</sup> The SEPC questionnaire has since been adapted into a 23-item questionnaire, with questions grouped into three main categories pertaining to communication, patient management, and multidisciplinary teamwork. Respondents are required to rate their perceived self-efficacy using a 100mm visual analogue scale (VAS) in relation to their skills and behaviours pertaining to each of the above categories. The VAS is anchored from 'very anxious' at 0mm to 'very confident' at 100mm.

The justification for using the SEPC questionnaire for this part of the study is based on the following:

- The SEPC scale has been shown to be a valid and reliable tool through which the impact of undergraduate palliative care education programmes can be assessed, <sup>(130)</sup> with meaningful assessment of the concept of self-efficacy amongst medical undergraduates. <sup>(121)</sup>



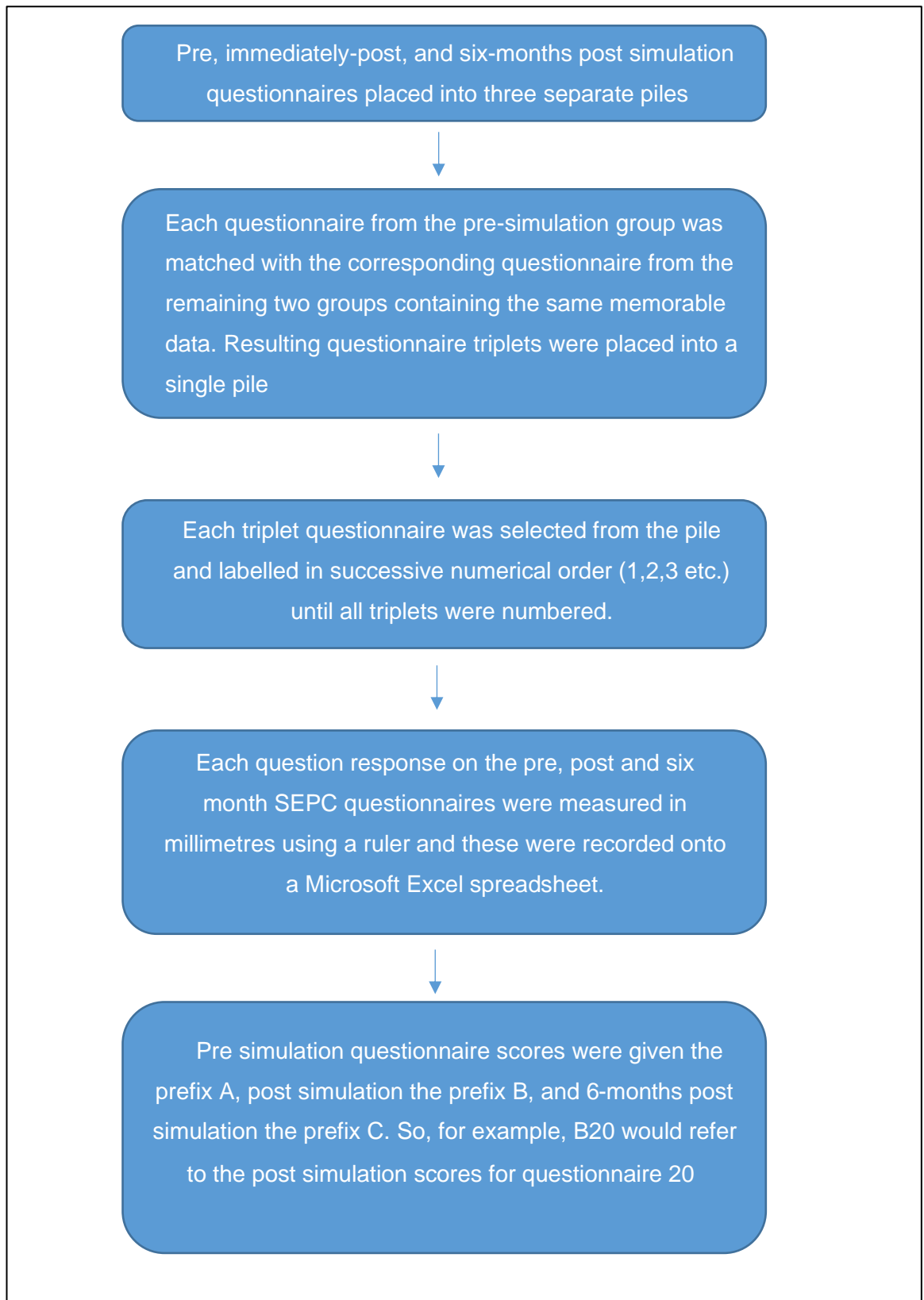
- The results of the earlier systematic review found the SEPC to be the only validated tool with documented evidence for use in measuring medical student confidence in the specific care of dying patients.<sup>(140)</sup>

### 3.8.2 Data collection

The SEPC was distributed at three separate time points during the course of this study. The first pre-simulation SEPC questionnaire was sent to students one week in advance of their allocated simulation day. A second SEPC questionnaire was emailed to students in the week following the simulations. Students were asked to complete this questionnaire and email it back to the primary researcher as soon as they could. The third and final SEPC questionnaire was sent to students exactly six months after the date of their individual simulations and once again students were asked to complete this as soon as they could. Questionnaires were pre-labelled with the specific time point (pre-simulation, post-simulation, or six-months post-simulation) at which they were distributed so that questionnaires from all three time points were distinct.

### 3.8.3 Data measurement and transfer

In order to facilitate collation of the questionnaires, students were asked to mark each of their three questionnaires with the same unique word, picture or phrase at the time of completion. It was explained this memorable data must not contain any personally identifiable data. Questionnaires were returned by secure university email. All returned questionnaires were printed off and underwent a process of collation and data transfer as detailed in figure 3.1.



**Figure 3.1 Process of SEPC questionnaire data collation and transfer**

#### 3.8.4 Quality control of data measurement

Four sets of triplet questionnaires (12 questionnaires in total) were selected at random by an independent reviewer (EY) to undergo repeat measurement. This was to represent 10% of SEPC data. The research team agreed that an error of measurement of +/- 1mm would be acceptable, as this represented the smallest unit of measurement at which an error could occur. Any measurement outside this error would necessitate a further 10% of questionnaires to be independently measured. Following this, if further errors of greater than 1mm were found, this would warrant re-measurement of the entire dataset.

Given the SEPC questionnaire requires the respondent to mark their confidence on a line between two anchor statements, it was possible that an individual's score may sit between one millimetre and the next. For consistency the primary researcher and independent reviewer (EY) agreed that any score marked at 0.5mm or above will be rounded up to the nearest whole millimetre, and anything less than 0.5mm rounded down.

To quantify the level of consistency between the scores recorded by both the primary researcher and independent reviewer, all measurements for related questionnaires were subjected to inter-rater reliability testing.

#### 3.8.5 Statistical methods

As with study 2, descriptive statistics were used to summarise data. Distributions of SEPC data were examined for normality at all three time points. Means and standard deviations were reported for normally distributed variables, medians and interquartile ranges reported for non-normally distributed variables. Kolmogorov-Smirnov (KS) tests were applied to further assess degree of normality within data distribution, providing additional evidence to support the choice of tests to be used for data analysis of data between the different time points.

Paired t-tests (parametric) and Wilcoxon Signed Rank tests (non-parametric) were applied to compare the differences between the pre and post-simulation data, pre and six-month data, and post-simulation and six-month data depending on whether the data was normally distributed or skewed respectively. Three group comparisons used a repeated-measures analysis of variance (ANOVA) or Kruskal-Wallis test for continuous and skewed data respectively to identify

whether there was a significant difference between the mean SEPC scores over the three time points. These tests were only applied where relevant assumptions for these tests were met. Where significant results were found, pairwise examinations were undertaken to identify the specific time points to which the significant results could be attributed. During pairwise comparisons it was necessary to apply the Bonferroni correction, an adjustment that is made to p-values when several statistical tests are being performed simultaneously on a single data set.<sup>(94)</sup> As with study 2, all p-values are presented as 2-tailed, with significance defined as  $p < 0.05$ . 95% confidence intervals are provided for all parameters.

### 3.8.6 Statistical support for both studies

Data was collated using Microsoft Excel (2016), with statistical analysis being undertaken using IBM SPSS (Version 25) alongside support from the BSMS statistics department.

### 3.8.7 Conclusion

This chapter has described the specific methodologies used to conduct and analyse the two separate studies conducted as part of this thesis. For both studies a rationale has been provided for the choice of study design, study population and sample size. Details of the reporting guidelines being used have been explained. In-depth procedural methodology for both studies has been provided, along with details regarding ethical considerations, potential for bias, data handling, and methods used for statistical analysis. For the qualitative component of study 3, the underpinning educational and learning theories have been outlined, and these are explored further with respect to the qualitative results.

Results for both study 2 and study 3 are presented in chapters 4 and 5 respectively.

## **Chapter 4: A study of student attitudes towards caring for a dying person and their family (Empirical Study 2)**

### **4.1 Introduction**

The main introduction to this thesis explored the distress reported by newly qualified doctors with respect to caring for someone who is dying. In particular, it has been suggested that distress amongst FY1 doctors can be partly attributed to a general lack of preparation at undergraduate level, with studies finding that in many cases students feel they are steered away from seeing the very sick and dying whilst attached to clinical placements.<sup>(12)</sup> Furthermore, reports demonstrate that the type and depth of palliative care (and care of the dying) teaching students receive is largely dependent on which medical school they attend.<sup>(17, 19, 50)</sup> Although most medical schools follow an individualistic approach when deciding how to teach these subjects, recent studies have begun to see significant progress being made with respect to the consistency and homogeneity of end of life care teaching at undergraduate level.<sup>(51)</sup>

Contemporary literature reports on the benefits of additional postgraduate training of junior doctors in palliative and end of life care, particularly communication skills.<sup>(141, 142)</sup> The mandate for providing such training takes us back to the points made in chapter 1, where junior doctors continue to report leaving medical school insufficiently prepared to have such conversations or to provide such care.<sup>(12, 15, 143)</sup>

This is not necessarily an issue unique to undergraduate medicine. Of all healthcare professionals, nurses spend the most time with dying patients, and yet many of our nursing colleagues do not gain experience of caring for the dying until after they have qualified.<sup>(144)</sup> A 2016 cross-sectional study conducted in the UK sought to identify student nurses' attitudes towards care of the dying. Of the 567 students who participated, over 90% were found to demonstrate a positive attitude towards care of the dying. Interestingly, the study found that higher scores (equating to a more positive attitude) were found in those students in their third year of study (compared to 1<sup>st</sup> year of study) (CI=0.36-4.01, p=0.017), those who had been directly involved in caring for dying patients (CI=1.09-4.08, p=0.002), those caring for a dying friend or relative (CI=0.69-3.37, p=0.003) or who had prepared a body after death (CI=0.57-3.87), p=0.008). Differences seen as a result of age and gender were not found to be significant.<sup>(145)</sup>

It appears that less is known about the attitudes of medical students with respect to caring for the dying, and this is what was explored in this first study.

## **4.2 Aim**

To gain an understanding of BSMS medical students' attitudes with respect to caring for someone who is dying, and identify whether these attitudes are influenced by variables of age, year of study, gender identity, or having obtained a previous undergraduate degree.

## **4.3 Methods**

A detailed description of the methodology used for this study are provided in chapter 3. Any medical student currently studying on the undergraduate medicine course at BSMS was eligible to participate, with students asked to complete the chosen study questionnaire at a single time point. The results of this study are reported in line with the STROBE guidelines.<sup>(125, 126)</sup>

## **4.4 Results**

### **4.4.1 Questionnaires returned**

A total of 332 Thanatophobia Scale (TS) questionnaires were completed out of an eligible student population of 715, representing a return rate of 46.4%.

Table 4.1 displays a breakdown of responses per year. Although the greatest number of questionnaires were returned from the year 1 students (n=79), the greatest proportion of responses were returned from year 2 students (n=77), representing 57.9% of the year 2 cohort. The year 5 cohort returned the least number and proportion of questionnaires, with forty-five (28.7%) questionnaires returned.

**Table 4.1 TS questionnaires returned by each student year**

<b>Study year</b>	<b>Total number of students in year</b>	<b>Total number of questionnaires returned</b>	<b>Percentage representation</b>
<b>1</b>	161	79	49.1%
<b>2</b>	133	77	57.9%
<b>3</b>	141	61	43.3%
<b>4</b>	123	70	56.9%
<b>5</b>	157	45	28.7%

#### 4.4.2 Missing data

Out of the 332 questionnaires returned, 315 (94.9%) contained no missing data of any kind. The remaining 17 (5.1%) questionnaires contained missing data to varying degrees.

##### 4.4.2.1 Missing demographic data

In total, 15 (4.5%) questionnaires were missing some or all demographic data.

One (0.3%) questionnaire was solely missing data pertaining to age, and one (0.3%) was solely missing data pertaining to degree status. Although the impact of these missing variables on TS score could not be measured, analysis of remaining variables for which data were present was still possible.

Thirteen (3.9%) questionnaires were missing all three demographic data points pertaining to age, gender identity and degree status. For these questionnaires it was not possible to analyse the impact of those missing variables on TS score. However, completed TS scores within these questionnaires were still used to analyse the effect of the 'year of study' variable. This was possible because the specific year of study had been pre-printed on each questionnaire for the year group to which it was being distributed, and as such this data was guaranteed on all returned questionnaires.

#### 4.4.2.2 Missing TS scores

Two (0.6%) questionnaires were missing numerical data within the TS score itself. Of these, one (0.3%) questionnaire was missing data for question three, and one (0.3%) questionnaire was missing data for question five. Through discussion with the study team it was felt that this represented a low level of missing data and as such it would be possible to statistically impute missing scores. Therefore, the mean score achieved from the remaining six questions within the same questionnaire was calculated and used to represent the missing score. This was done for both questionnaires with missing data, and once completed full analysis of the dataset was commenced.

#### 4.4.3 Study population demographics

Table 4.2 displays basic demographic data for all students where completed.

The median student age was 22, with an age range of 17 to 52 years. There was no difference in median age observed between male and female participants. The majority of participants were female (67.4%), and 44% of students had obtained a previous degree (whether prior to starting medical school or through intercalation during medical school studies).

Of those with a previous degree (n=140), 67.1% were female and 32.9% were male, and this reflected the same ratio of gender identity observed in the study population.



**Table 4.2 Demographic details for all students.**

Variable		N (%) <sup>a</sup>
Age		mean = 23.2 (SD 4.84) median = 22 (IQR 20-24)
Age range		17-52
Gender identity	Male	104 (32.6)
	Female	215 (67.4)
Previous degree	Yes	140 (44.0)
	No	178 (56.0)
<sup>a</sup> Unless stated		

#### 4.4.4 Data distribution

To inform the choice of analytical tool to be used in the analysis of thanatophobia scores, the degree of normality within the data distribution was determined by creating and visualising Probability-Probability (PP) and Quantile-Quantile (QQ) plots for data variables (Appendix K). Following discussion with the supervisory team and the statistician, residual data represented by these graphs were felt to follow an approximately normal distribution. As such a multivariate regression was chosen by which to further analyse the data. This is because the relevant assumption for the use of multivariate analysis is that residuals within the data should be approximately normally distributed.

#### 4.4.5 Thanatophobia score interpretation and analysis

The minimum TS score any individual can achieve is 7, the maximum is 49. The higher an individual's TS score, the higher their degree of thanatophobia (anxiety in relation to caring for a dying patient and their family). There is no consensus within the literature as to what score would constitute a high degree or low degree of thanatophobia, more a focus on the difference in score between groups or individuals, and the degree of change seen.

A multiple linear regression model was created to determine what effect, if any, the independent variables of age, gender identity, degree status, and year of study would have on the outcome variable TS score. Given the small number of

independent variables, data was entered into the model at the same time using the entry method. Table 4.3 displays results of the multivariate analysis.

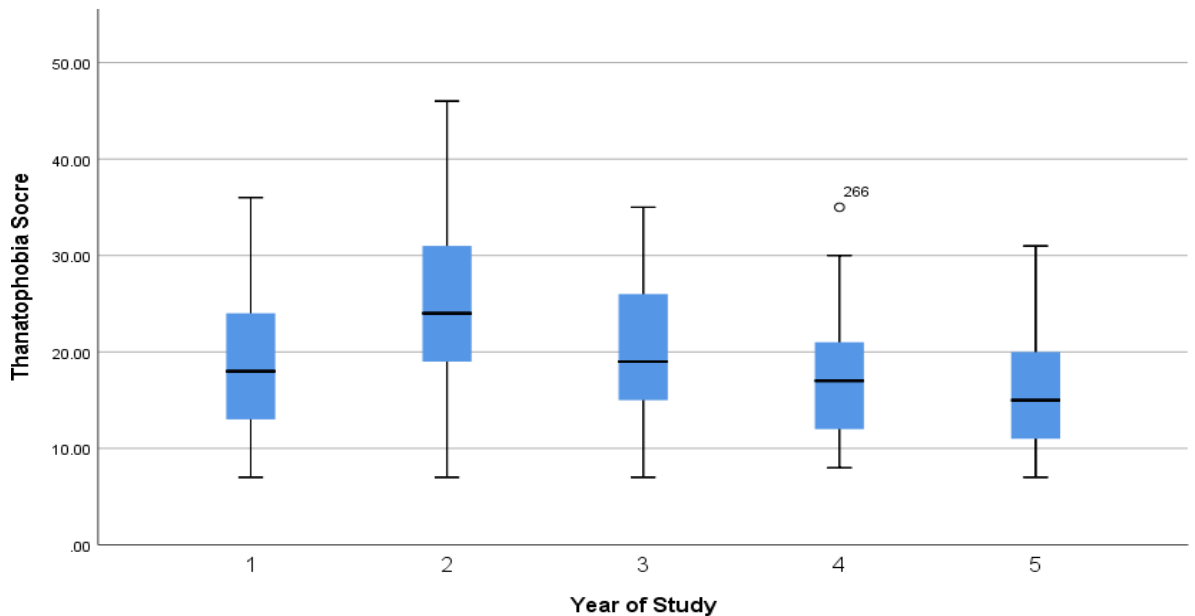
**Table 4.3 Multivariate analysis of TS score**

Independent variable	Unstandardised Coefficient	Standardised Beta Coefficient	95% Confidence Interval	p-value
Age	-0.282	-0.174	-0.473 – -0.091	0.004
Gender identity	1.477	0.088	-0.210 – 3.164	0.086
Previous degree	-1.176	-0.075	-3.026 – 0.674	0.212
Year 2	6.088	0.326	3.778 – 8.398	<0.001
Year 3	1.969	0.096	-0.540 – 4.478	0.124
Year 4	-0.115	-0.006	-2.548 – 2.317	0.926
Year 5	-0.409	-0.018	-3.302 – 2.485	0.781

The most significant influence on TS score was seen in relation to year of study (Graph 4.1 & Table 4.3). Each year was compared to that of year 1, and results demonstrate that being a student in the second year of study increased the TS score by 6.088 (CI 3.778 – 8.398,  $p < 0.001$ ). This provides strong evidence that second year students possess a higher degree of thanatophobia towards caring for a dying patient and their family, than that of their peers in any of the other year groups.

Whilst there was a trend towards a small increase in TS score within the year 3 cohort (1.969, CI -0.540 – 4.478), this finding was not found to be statistically significant ( $p = 0.124$ ).

Figure 4.1 provides an overall visualisation of the change in thanatophobia score for each year of study. The general trend seen on the graph is that of a fall in thanatophobia score from a mean score of 18.67 (SD 7.39) in the 1<sup>st</sup> year of study, to a mean score of 15.76 (SD 6.09) by the 5<sup>th</sup> year of study.

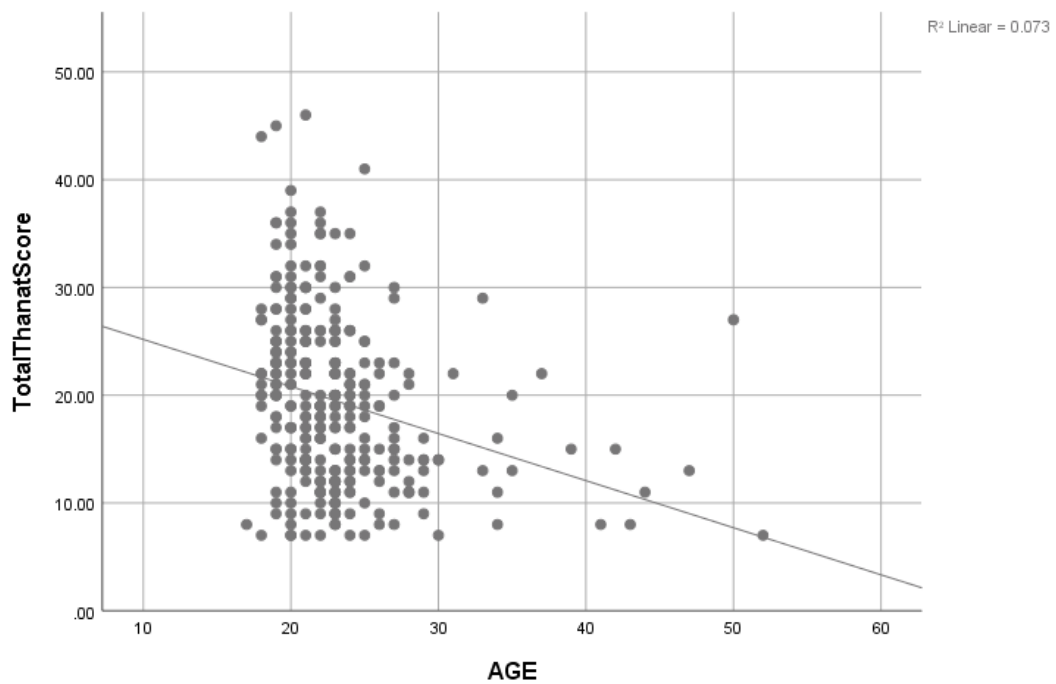


**Figure 4.1 Boxplot of thanatophobia score by year of study**

Participant age exerted a small but significant influence on TS score (Figure 4.2 & Table 4.3). For an increase in age of 1 year, the TS score changed by  $-0.282$  (CI  $-0.473 - -0.091$ ,  $p=0.004$ ). This provides strong evidence that for every 3.5-year increase in age, the TS score will fall by 1 point (2.5%), corresponding to a lower level of thanatophobia.

Results suggest a trend towards a higher level of thanatophobia in female students compared to that of their male peers, with an average increase in TS score of  $1.477$  (CI  $-0.210 - 3.164$ ) amongst female participants. However, this was not statistically significant ( $p=0.086$ ).

Students with a previous degree ( $n=140$ , 44.0%) demonstrated a TS score that was  $1.167$  lower (CI  $-3.026 - 0.674$ ) than that of students without a degree. Whilst this may suggest a trend towards a lower level of thanatophobia within this group, there is no evidence to support this finding ( $p=0.212$ ).



**Figure 4.2 Scatter plot demonstrating decrease in TS score with increasing age**

#### **4.5 Discussion**

The results of this cross-sectional study have demonstrated that anxiety in relation to caring for a dying patient and their families is greatest amongst younger students studying at BSMS. It has also demonstrated that those students in their second year of study have greater anxiety about caring for a dying patient than any other year group.

The study found that degree status and gender identity had no significant effect on level of thanatophobia amongst our students.

Discomfort, feelings of helplessness and frustration (thanatophobia) is not an uncommon finding amongst medical students. Older studies have demonstrated that a greater degree of fear and anxiety can be seen in medical students when compared to that of other healthcare colleagues (student nurses, nurses, qualified senior doctors).<sup>(146)</sup> One reason as to why medical students and trainee doctors experience greater fear about death and dying compared to nursing colleagues may be due to the expectations of each professional group. It has been suggested that medical students often follow a biomedical model of disease,

with the expectation that they must strive to cure their patients, whereas nursing colleagues are more likely to focus on the individual patients' problems as caused by the underlying disease without necessarily expecting curative intent.<sup>(127)</sup>

Results echo those found in studies conducted both in the UK and USA which demonstrate that a higher level of thanatophobia can be seen amongst younger medical students when compared to older students.<sup>(127, 147)</sup> Whereas literature suggests medical students' expectation of curative intent for their patients may be a factor for increased thanatophobia when compared to nursing colleagues, it also suggests that increasing student age is associated with a more positive view on caring for terminally ill patients rather than curing.<sup>(147)</sup> A more recent (2019) Korean study exploring attitudes towards end of life care amongst medical students found that whilst differences as a result of gender identity were inconsistent, older students (greater than 26 years old) and graduates were statistically more interested in end of life care in general. It is important to note that this study did not specifically look at thanatophobia amongst the student population.<sup>(148)</sup>

There is less in the literature that supports why our study found that second year BSMS students possess a higher degree of thanatophobia than that of any other year group, however there are several reasons as to why this may have occurred.

The vast majority of palliative care teaching at BSMS occurs in the fourth year of training, with students receiving a minimum of 23 hours mandatory palliative care teaching during this academic year. Prior to this there is no formal palliative care teaching in year 1 of the course, 6 hours of palliative care-related (but not dedicated) teaching in year 2, and 1.5 hours mandatory palliative care teaching in year 3. The TS questionnaire was distributed in the first half of the academic year, therefore the second-year students will have only received a maximum of 6 hours non-dedicated palliative care teaching at that time.

It is important to recognise that the 1<sup>st</sup> and 2<sup>nd</sup> years of undergraduate medicine at BSMS are in general much less clinically orientated than years 3-5. Results of early studies into medical student attitudes on death and dying have shown that clinical placement can have a positive effect on students' fear of the death of others,<sup>(149)</sup> which may suggest that exposure to patients and patient death may be a factor that can positively change attitudes towards death and dying.

The 2nd year group is unique in that it represents those students who are due to commence full-time clinical attachments in under 12 months' time. Anticipation of the change they will experience as they enter their clinical years may lead to feelings of increased anxiety. It would be interesting to see if, as a cohort, they are increasingly anxious about other aspects of clinical placement such as prescribing practice, diagnostics or medical management of common conditions in order to identify whether their anxiety is more generic rather than subject specific. Any future studies could control for general anxiety in their data analysis.

With the exception of a proportion of 5<sup>th</sup> year students who were contacted by email, all remaining students were contacted in person either before or after a lecture. It is possible that the nature of the lecture students received immediately before completing the questionnaire, or were about to receive immediately after, could themselves have provoked increased anxiety within the 2<sup>nd</sup> year group. In turn this could have impacted the way students in this cohort scored the questionnaire.

It is entirely possible this result may have occurred due to the low numbers of participants in each year. Despite the second year group returning the greatest proportion of results of any other year (57.9%), there were still only 77 completed questionnaires. This number may be small enough to allow for statistical errors to occur affecting the overall result.

In contrast to the findings in this study, a previous study of students in a large UK medical school found overall death anxiety levels remained stable throughout the length of their medical course, with an actual increase in student anxiety specifically in relation to death of patients only seen during the clinical component of the course.<sup>(150)</sup> However, the study did not measure responses from their 2<sup>nd</sup> year cohort so it is difficult to make direct comparisons to our findings.

Another perspective in relation to the findings between year groups is whether the first-year cohort may have an unusually low level of thanatophobia, therefore making the second-year cohort appear higher in comparison. This could be the result of a lack of self-awareness about death and dying. This would make sense as the first year cohort will have received no palliative or end of life care teaching when the questionnaires were distributed.

Developed in 1955 by Luft and Ingham,<sup>(151)</sup> the Johari window, (Figure 4.1) is a psychological matrix that can be used to enable us to understand our own behaviours, feelings and motivations in relation to interpersonal interactions, and may be helpful to illustrate this point. As first year students have not been exposed to any palliative or end of life care at the point of completing the study questionnaire, their responses may fall into the 'unknown to self and others' area, in other words, they don't know what they don't know. Without understanding what care of the dying entails, it may be hard for them to feel anxious about it, especially when they are at least 18 months away from their first full-time clinical placement, and at least 4 ½ years away from qualification.

	Known to self	Not known to self
Known to others	'Open self' (You know what you know)	'Blind self' (You don't know what you know)
Not known to others	'Façade' (You know what you don't know)	'Hidden self' (You don't know what you don't know)

**Figure 4.3 Johari Window**

It is important to appreciate that anxiety may not always be a bad thing. Whilst there is a negative relationship between academic performance and high levels of anxiety, studies acknowledge that a low-level of performance anxiety can actually have beneficial effects on performance and achievement.<sup>(152, 153)</sup> This may be because a degree of anxiety suggests that the outcome of your action is important to you, that it is meaningful, and that you want to do a job well. The way in which we deal with anxiety differs, and can range from developing a plan of action to deal with the anxiety-provoking event, to avoidance of the situation

altogether.<sup>(153)</sup> To some degree it could be argued that a low level of anxiety may be protective for clinicians, and their patients, as it may mean they are more likely to double check clinical decisions (prescribing, diagnostic) with a colleague rather than be complacent and risk making an error.

Students at BSMS encounter death early on, with cadaveric teaching taking place in the second week of the first academic year. Students are taught about the importance and privilege of body donation, gain an understanding of the ethical principles involved, and receive a lecture from the relative of a donor. The care a body receives after death should be afforded the same respect and importance as that received during life, and where possible every effort should be made to respect the wishes of the deceased when it comes to donation of their body for the purposes of medical teaching.<sup>(43)</sup> It may be that the reality of death increases the closer students get to clinical placement, with the knowledge that they may be involved in the care of a patient who may themselves be donating their bodies to medical science. This could offer some explanation as to why the second year students report a higher level of thanatophobia.

Despite the changes seen in relation to year of study, what we have demonstrated is that thanatophobia level decreases with increasing age. Therefore, as students naturally age through the course, it is likely they will experience a diminishing degree of anxiety in relation to caring for someone who is dying.

#### 4.5.1 Strengths and Limitations

There has been very little documented about thanatophobia amongst medical students in the UK, and how this changes as students' progress through medical school. In addition, we have looked at whether age, gender identity, and degree status has any significant influence on level of thanatophobia. We aimed for participants in this study to be as representative as possible to the UK undergraduate medical student population, and as such invited all students studying at BSMS to participate. One of the strengths of this study is that all data were collected within a 2-week time period, so as to provide a genuine snap-shot view of the dependent variable being measured.



A further strength of this study is the fact that the TS questionnaire has previously been validated for use in medical undergraduates and was the main justification for using this scale. Further justification was found when looking at the length of the scale and the time taken to complete it. This was important because if the questionnaire took longer than five minutes to complete then students would be less likely to complete it.

There are several limitations within this study. Whilst all students were invited to participate, less than 50% of students completed the TS questionnaire. Response rate was particularly low for the 5<sup>th</sup> year cohort, with only 28.7% of this group represented in the final results. This is likely to be due to the fact that the mode of contact for the 5<sup>th</sup> years was different to that of the other years, and was the result of the dispersed nature of this group at the time of data collection.

Whilst this study aimed to carry out a cross-sectional view of thanatophobia, it is important to recognise that there will be differences between each year cohorts. Whilst multivariate analysis will attempt to correct for some of these differences, it will only have corrected for those variables measured. With the benefit of time, a more robust study would be to follow the same year group through all 5 years of medical school whilst measuring their thanatophobia level on an annual basis. That way differences in the group would be kept to an absolute minimum and a clearer picture of how thanatophobia might change would be seen.

Opportunities to gather additional data have been missed and could have been added to the demographic data requested on the TS questionnaire. In particular, it may have been interesting to look at whether thanatophobia differed as a result of ethnicity, or exposure to previous encounters with death and dying.

Further strengths and limitations can be identified in relation to the use of a cross-sectional study design. The aim for empirical study 2 was to look at student attitudes at one point in time for all year cohorts, and look to identify differences across cohorts in terms of demographics such as gender identity and degree status, as well as differences between cohorts in terms of academic year of study.

Cross-sectional studies have the benefit of being able to be conducted at a single point in time, with a relatively low impact in terms of financial and time costs to the researcher. The main disadvantages to this type of data collection is that differences as a result of time will not be measured, and differences between

characteristics within two or more cohorts will exert an influence on the results if not corrected for (the 'cohort effect').<sup>(154)</sup> Published cross-sectional studies each measuring the same construct often report a mixed picture in terms of outcomes and may well be the result of between-group differences as well as external influences at the point of data collection.<sup>(155)</sup> In contrast longitudinal studies will take repeat measures of the same construct in the same individuals over a period of time which will greatly reduce any between-group differences, and largely correct for external influences observed at single time points.<sup>(154)</sup> Unlike cross-sectional studies, longitudinal studies are disadvantaged by the risk of participant attrition as well as the higher cost and time it takes to gather data.

#### **4.6 Conclusion**

This study has found that student age and year of study affect the level of anxiety medical students experience with respect to caring for a dying patient and their family. These findings echo results found in similar studies within nursing literature which has found that younger student nurses and those in earlier years of study possess a greater degree of thanatophobia. Very few studies have looked at thanatophobia amongst medical students, and this study adds a further depth of understanding to the existing literature particularly with regard to the degree of thanatophobia in relation to variables of student age, gender identity, degree status and year of study. The most unusual finding within this study was the discovery that second year students possess the greatest degree of thanatophobia, and several reasons as to why this may be the case have been postulated and discussed.

The next chapter in this thesis reports findings of the simulated intervention (study 3), identifying whether simulation can improve medical student confidence to care for the dying in a sustainable way.

## **Chapter 5: A study to determine whether simulating the care of a dying patient has any effect on student confidence and preparedness (Empirical Study 3)**

### **5.1 Introduction**

The methodological processes involved for both aspects of this study are reported in Chapter 3, but in summary the quantitative aspect reports the outcomes of a simulated teaching intervention on the care of a dying patient, with pre, immediately post, and six-months post simulation measures of confidence using a validated tool. Qualitative data pertaining to student preparedness and their views about the study simulations and current undergraduate curriculum was collected through post-simulation focus groups.

Chapter 1 described the challenges faced by junior doctors in modern medicine, with increasing demands and expectations in care provision. It can be guaranteed that every FY1 doctor will look after several dying patients in their first year post-qualification given that more than 50% of all UK deaths occur in a hospital setting.<sup>(29)</sup> Sadly many junior doctors continue to experience anxiety and distress when looking after the dying as they are often left to manage such patients on their own particularly when working on the wards out-of-hours.<sup>(16)</sup> Many junior doctors lack confidence to care for the dying and report a desire to see greater representation of palliative care within undergraduate curricula.<sup>(47)</sup>

There is increasing evidence of a positive correlation between improved self-efficacy and clinical performance,<sup>(73, 74)</sup> with self-efficacy itself strongly associated with confidence in one's ability to meet educational and learning objectives.<sup>(70, 71)</sup> The quantitative aspect of this study set out to determine whether a novel simulated teaching intervention involving the care of a dying patient and their family could have a positive lasting effect on student confidence to provide such care. The design of the simulated intervention was refined and developed following outcomes of a feasibility study undertaken and published by the primary researcher.<sup>(80)</sup>

The decision to use the validated Self-Efficacy in Palliative Care (SEPC) tool to measure student confidence at all three time points was made following the outcomes of the published systematic review reported in Chapter 2.<sup>(140)</sup>

Quantitative results will be reported and discussed first within this chapter.

Whereas confidence is a subjective measurement of one's ability to perform certain tasks, preparedness relates to how well students feel the education provided to them will enable them to perform their job, or a specific aspect of it. In doing so education will give students the opportunity to develop confidence.<sup>(156)</sup> Whilst recognising some degree of overlap, contemporary literature makes a distinction between the concepts of confidence and preparedness as discussed in chapter 1, and as such these two concepts have been treated as separate entities within this study.

## **5.2 Aim**

The overarching aim for study 3 was to ascertain whether simulation can improve medical student confidence and preparedness to care for a dying patient and their family.

## **5.3 Methods**

The methodological process for both quantitative and qualitative aspects of this study have been detailed in chapter 3. In summary, each half-day of simulations were followed by a single focus group. In total there were 8 half-days of simulations, and 8 focus groups. Results of the quantitative aspect of the study are reported in line with the STROBE criteria,<sup>(126)</sup> and results of the qualitative aspect are reported following the COREQ checklist.<sup>(135)</sup>

## **5.4 Results from quantitative data collection**

### **5.4.1 Study population**

The entire 4<sup>th</sup> year cohort (n=123) were contacted before the target of 40 (32.5%) volunteer participants was reached. Of the 123 students contacted, 17 (13.8%) declined to participate, 3 (2.4%) initially agreed to participate but withdrew due to personal circumstances, and 63 (51.2%) did not respond.

All simulation slots were filled several weeks in advance of the set simulation dates. However, 2 students (5%) withdrew their offer of participation in the week leading up to their allocated simulation. Whilst they were not required to give reasons for doing so, individuals voluntarily explained that personal circumstances and an overlooked prior commitment were responsible for their withdrawal. Despite best efforts, it was not possible to re-allocate these two slots at such late notice. As a result, a final total of 38 students (95%) participated in the simulations and focus groups. All eight groups initially contained 5 students each (n=40), however following withdrawal of the two students the final simulation groups consisted of six separate groups of 5 students, and two separate groups of 4 students (n=38)

#### 5.4.2 Self Efficacy in Palliative Care (SEPC) interpretation and measurement.

In contrast to that of the TS score, the SEPC questionnaire uses a 100mm Visual Analogue Scale (VAS). The scale is anchored with 'very anxious' at 0mm, to 'very confident' at 100mm. Therefore, the higher the score (in mm) achieved, the greater confidence the participant has in relation to the statement being scored. SEPC questions are grouped to form three sub-categories pertaining to communication skills (Q1-8), patient management (Q9-16) and MDT working (Q17-23). Whilst the mean scores achieved within each time point of pre-simulation, immediately post-simulation, and six-months post-simulation are described, it is the difference of the means between each time point that will be of greatest interest, as this will serve to demonstrate what change in confidence level (if any) has occurred and whether this is statistically significant.

#### 5.4.3 Errors in scale measurement

During the process of questionnaire measurement, it became apparent that not all statements had a corresponding VAS which measured exactly 100mm, and the length of the scale appeared to differ between individual questionnaires. This is likely to have occurred as a result of participants marking their VAS electronically, and in doing so inadvertently increasing or reducing the length of the scale depending on the font size they used to mark their point along the scale. In order to ensure standardisation of the scales, the primary researcher measured

both the score as well as the length of the scale for each statement in every questionnaire, and entered this data onto an Excel spreadsheet. The raw score obtained (in mm) was divided by the length of its scale (in mm) before being multiplied by 100. Doing this ensured that each score was standardised to a 100mm scale.

#### 5.4.4 Inter-rater reliability

Reliability of questionnaire measurements was determined for the 10% of corresponding scores measured by the both independent reviewer (EY) and primary researcher. Interclass correlation coefficient for average measures (Table 5.1) was found to be 0.997 (CI 0.996 - 0.997,  $p < 0.001$ ) suggesting a high level of inter-rater agreement.

**Table 5.1 Measure of inter-rater agreement**

	Intra-class correlation	95% Confidence Interval		Sig
		Lower bound	Upper bound	
<b>Average measures</b>	.997	.996	.997	<0.001

#### 5.4.5 Pre-simulation questionnaires

In total all 38 pre-simulation SEPC questionnaires were returned, and contained no missing data.

##### 5.4.5.1 Tests for normality

Table 5.2 displays distribution data with respect to pre-simulation SEPC results. No significance has been demonstrated with respect to the Kolmogorov-Smirnov (KS) tests for all three sub-categories. From this it can be said that there is a trend in the data that favours more of a normal distribution than that of a skewed distribution, as such it would be reasonable to analyse this dataset using parametric tests.

**Table 5.2 Distribution of pre-simulation SEPC data**

	Mean	SD	Kolmogorov-Smirnov	
			Statistic	Significance (Asymp.Sig)
<b>Pre-simulation communication skills</b>	32.84	17.10	.117	p=0.200
<b>Pre-simulation patient management</b>	38.20	14.05	.138	p=0.66
<b>Pre-simulation MDT working</b>	37.76	15.24	.099	p=0.200

#### 5.4.5.2 Findings

Table 5.3 displays the results of the pre-simulation SEPC scores. Data includes the minimum and maximum mean scores achieved at an individual level for all three sub-categories. Finally, the cohort mean score is presented for each sub-category along with the standard deviation (SD).

These data demonstrate that at the pre-simulation time point, a wide range of scores have been documented amongst the participatory group. Some individuals have recorded a low level of confidence (mean score 5.0mm) with respect to communication skills, whilst others have scored a much higher level of confidence in comparison (mean score 78.0mm). The mean cohort score for this subcategory demonstrates that participants as a whole placed their confidence score at approximately one-third along the 100mm SEPC scale, with 95% of data points (2 SD) being scored on the lower half of the SEPC scale (range 15.7 – 49.9mm).

With respect to patient management the mean cohort score was higher at 38.2mm, with 95% of scores falling between 24.2 - 52.2mm suggesting students felt more confident in their patient management skills than their communication skills.

Finally, the MDT working subcategory followed a similar pattern to that of communication skills, scoring a mean of 37.8mm, with 95% of scores falling between 22.5 – 53.0mm.

Overall the majority of students have scored in the lower half of the SEPC scale at the pre-simulation stage for all three subcategories, which suggests a low level of confidence within the study group.

**Table 5.3 Pre-simulation mean minimum, maximum and cohort scores (n=38)**

Pre-simulation SEPC sub-categories	Minimum individual score (mean, mm)	Maximum individual score (mean, mm)	Mean cohort score (mm)	SD (mm)
Communication skills (Q1-8)	5.00	78.00	32.84	17.10
Patient management (Q9-16)	0.00	57.50	38.28	14.05
MDT working (Q17-23)	7.14	70.00	37.76	15.24

#### 5.4.6 Immediately post-simulation questionnaires

In total 38 immediately post-simulation questionnaires were returned, with no missing data identified

##### 5.4.6.1 Tests for normality

As with the pre-simulation results KS tests were applied to the immediately post-simulation data. The KS results did not demonstrate any statistical significance, therefore the immediately post-simulation data was deemed to follow a normal distribution and as such parametric tests were used in the further analysis of this data. KS results are displayed in Appendix L.

##### 5.4.6.2 Findings

Table 5.4 tabulates the mean scores for all participants pertaining to the three subcategories at the immediate post-simulation time point.

In comparison to the pre-simulation scores, mean cohort scores increased from 32.8mm to 64.9mm for communication skills (97.9% increase), from 38.2mm to 63.5mm for patient management (66.2% increase), and from 37.8mm to 56.1mm for MDT working (48.4% increase) in the immediate post-simulation time point.



In contrast to the pre-simulation results, 95% of SEPC scores were found to be in the upper half of the 100mm scale for both communication skills (range 53.0 - 76.8mm), and patient management (range 50.3 – 76.7mm). In terms of MDT working students tended to score this slightly lower, with 95% of scores being marked between 40.6 – 71.6mm.

**Table 5.4 Immediately post-simulation mean minimum, maximum and cohort scores (n=38)**

Post-simulation SEPC sub-categories	Minimum individual score (mean)	Maximum individual score (mean)	Mean cohort score	SD
Communication skills (Q1-8)	35.00	92.00	64.94	11.85
Patient management (Q9-16)	17.50	85.00	63.49	13.16
MDT working (Q17-23)	25.71	88.14	56.11	15.46

#### 5.4.6.3 Comparison of pre- and post-simulation scores

Differences between the mean pre-simulation and immediately post-simulation scores for all three domains are displayed in Table 5.5.

**Table 5.5 Pre-simulation and immediately post-simulation mean scores**

<b>Pairs</b>	<b>Mean</b>	<b>N</b>	<b>SD</b>	<b>Std. Error Mean</b>
<b>Pre-sim Com. Skills</b>	32.84	38	17.10	2.77
<b>Immediately post-sim Com. Skills</b>	64.94	38	11.85	1.92
<b>Pre-sim Pt management mean</b>	38.20	38	14.05	2.28
<b>Immediately post-sim Pt management</b>	63.49	38	13.16	2.13
<b>Pre-sim MDT working</b>	37.76	38	15.24	2.47
<b>Immediately post-sim MDT working</b>	56.11	38	15.46	2.51

Based on the results of KS testing, paired t-tests were used to compare the mean scores between the two time points (Table 5.6). There was a significant difference between pre-simulation communication skills (M=32.84, SD=17.10), and immediately post-simulation communication skills (M=64.94, SD=11.85) scores;  $t(37)=14.13$ ,  $p<.001$ .

There was also a significant difference in pre-simulation patient management (M=38.20, SD=14.05), and immediately post-simulation patient management scores (M=63.49, SD=13.16) scores;  $t(37)=10.85$ ,  $p<.001$ .

Finally, there was a significant difference in pre-simulation MDT working (M=37.76, SD=15.42), and immediately post-simulation MDT working (M=56.11, SD=15.46) scores;  $t(37)=9.34$ ,  $p<.001$

**Table 5.6 Paired samples t-test for pre-simulation and immediately post-simulation data.**

Pairs	Paired differences					t	df	Sig (2-tailed)
	Mean	SD	Std. Error Mean	95% Confidence Interval of the Difference				
				Lower	Upper			
<b>Immediately post-sim Com. Skills Mean – Pre-sim Com. Skills</b>	32.10	14.01	2.27	27.49	36.1	14.13	37	<0.001
<b>Immediately post-sim Pt management Mean - Pre-sim Pt management</b>	25.29	14.36	2.33	20.57	30.01	10.85	37	<0.001
<b>Immediately post-sim MDT working Mean - Pre-sim MDT working</b>	18.35	12.11	1.96	14.37	22.33	9.34	37	<0.001

df=degrees of freedom

#### 5.4.7 Six-months post-simulation results

In total, all 38 students returned their 6-month follow-up questionnaires.

##### 5.4.7.1 Missing data

During the process of data transfer onto Microsoft Excel (2016) and IBM SPSS Statistics (Version 25), it was noted there were areas of missing data within two six-month post-simulation questionnaires. Questionnaire C05 was missing scores for questions 16 and 17. Questionnaire C24 was missing data for questions 12-23 inclusive.

Through discussion with the research team it was decided that, for questionnaire C05, this represented minimal missing data. Furthermore, the missing questions were split across two category subsets within the SEPC, with question 16 pertaining to 'patient management', and question 17 pertaining to 'MDT working'. As such it was deemed appropriate to impute scores for these missing data points to enable the entire data set for C05 to be used in analysis. This was done in the same manner as that of the missing thanatophobia scores, with imputed scores

representing the mean score achieved from the completed data within each subset.

With respect to questionnaire C24, research team discussions concluded that the amount of data missing was deemed too significant to allow for imputation of scores. Whilst all data was present for communication skills questions 1-8, the majority of data were missing for patient management questions 9-16, and all data were missing for MDT working questions 17-23. Therefore, it was agreed that only the communication skills subcategory could be used in data analysis, meaning  $n=37$  for the remaining two incomplete subcategories within the six-month data.

#### 5.4.7.2 Tests for normality

The six-months post-simulation questionnaire results were also found to follow a normal distribution, with no significance found within KS test scores. (Appendix L). Based on this finding parametric tests (paired t-tests) were used in the further analysis of this data.

#### 5.4.7.3 Findings

Table 5.7 displays the six-month post simulation scores achieved within all completed questionnaires. At first glance the mean scores for communication skills and patient management do not appear to differ all that much from the immediately post-simulation scores, with mean scores for all three domains sitting between 60-70mm on the SEPC scale. Interestingly the mean score for MDT working is over 10mm higher than that seen from the immediately post-simulation questionnaires.

Whilst the minimum mean individual score is lower for communication skills in this dataset (compared to the immediately post-simulation score), both minimum mean scores are higher for patient management and MDT working domains.

What has not been demonstrated is a return to pre-simulation scores, despite a six-month time period having elapsed.

**Table 5.7 Six-months post-simulation mean minimum, maximum and cohort scores (n=38<sup>a</sup>)**

Six-months post-simulation SEPC sub-categories	Minimum individual score (mean)	Maximum individual score (mean)	Mean cohort score	SD
Communication skills (Q1-8)	30.35	91.13	64.08	12.29
Patient management (Q9-16) (n=37)	35.25	89.00	66.23	14.63
MDT working (Q17-23) (n=37)	34.29	98.86	66.85	14.18

<sup>a</sup> Unless otherwise stated

#### 5.4.7.4 Comparison of pre-simulation and six-months post simulation scores.

The mean pre-simulation and six-months post-simulation scores for all three domains are displayed in Table 5.8.

**Table 5.8 Pre-simulation and six-months post-simulation mean scores**

Pairs	Mean	N	SD	Std. Error Mean
Pre-sim Com. Skills	32.84	38	17.10	2.77
Six-months post-sim Com. Skills	64.08	38	12.29	1.99
Pre-sim Pt management mean	37.91	37	14.11	2.32
Six-months post-sim Pt management	66.23	37	14.63	2.41
Pre-sim MDT working	37.38	37	15.27	2.51
Six-months post-sim MDT working	66.85	37	14.18	2.33

Paired t-tests were applied to this data in the same manner to that of the pre-simulation and immediately post-simulation data. T-test results are displayed in table 5.9, and demonstrate a significant difference between pre-simulation communication skills (M=32.84, SD=17.10), and six-months post-simulation communication skills (M=64.08, SD=12.29) scores;  $t(37)=11.50$ ,  $p<.001$ .

There was also a significant difference in pre-simulation patient management (M=37.91, SD=14.11), and six-months post-simulation patient management scores (M=66.23, SD=14.63) scores;  $t(36)=9.52, p<.001$

Finally, there was a significant difference in pre-simulation MDT working (M=37.38, SD=15.27), and six-months post-simulation MDT working (M=66.85, SD=14.18) scores;  $t(36)=9.73, p<.001$

**Table 5.9 Paired samples t-test for pre-simulation and six-months post-simulation data**

Pairs	Paired differences					t	df	Sig (2-tailed)
	Mean	Std. Deviation	Std. Error Mean	95% CI of the Difference				
				Lower	Upper			
<b>Six-months post-sim Com. Skills Mean – Pre-sim Com. Skills Mean</b>	31.24	16.74	2.72	25.73	36.74	11.50	37	<0.001
<b>Six-months post-sim Pt management Mean - Pre-sim Pt management mean</b>	28.32	18.10	2.98	22.29	34.36	9.52	36	<0.001
<b>Six-months post-sim MDT working Mean - Pre-sim MDT working Mean</b>	29.46	18.42	3.03	23.32	35.60	9.73	36	<0.001

#### 5.4.8 Comparison of immediately post-simulation and six-months post-simulation SEPC scores.

The mean immediately post-simulation and six-months post-simulation scores for all three domains are displayed in Tables 5.4 and 5.7 respectively, and are compared in Table 5.10.

**Table 5.10 Immediately post-simulation and six-months post-simulation mean scores**

Pairs	Mean	N	SD	Std. Error Mean
Immediately post-sim Com. Skills	64.94	38	11.85	1.92
Six-months post-sim Com. Skills	64.08	38	12.29	1.99
Immediately post-sim Pt management	63.49	38	13.16	2.13
Six-months post-sim Pt management	66.23	37	14.63	2.41
Immediately post-sim MDT working	56.11	38	15.46	2.51
Six-months post-sim MDT working	66.85	37	14.18	2.33

Paired t-tests were applied to this data in the same manner as described earlier, given the KS test results as previously described for all three time points. Paired t-test results are displayed in table 5.11 and demonstrate there is no significant difference between immediately post-simulation and six-months post-simulation communication skills ( $M=-0.87$ ,  $SD=10.59$ ) scores;  $t(37)=-0.50$ ,  $p0.617$ . Equally there is no significant difference between the immediately post-simulation and six-months post-simulation patient management ( $M=3.13$ ,  $SD=13.81$ ) scores;  $t(36)=1.38$ ,  $p0.176$ .

However, a significant difference does exist between the immediately post-simulation and six-months post-simulation communication skills ( $M=11.38$ ,  $SD=17.52$ ) scores;  $t(36)=3.95$ ,  $p<0.001$ .

**Table 5.11 Paired samples t-test for immediately post-simulation and six-months post-simulation data**

Pairs	Paired differences					t	df	Sig (2-tailed)
	Mean	Std. Deviation	Std. Error Mean	95% CI of the Difference				
				Lower	Upper			
<b>Six-months post-sim Com. Skills Mean – Immediately post-sim Com. Skills Mean</b>	-0.87	10.59	1.72	-4.34	2.61	-0.50	37	0.617
<b>Six-months post-sim Pt management Mean – Immediately post-sim Pt management mean</b>	3.13	13.81	2.27	-1.47	7.73	1.38	36	0.176
<b>Six-months post-sim MDT working Mean – Immediately post-sim MDT working Mean</b>	11.38	17.52	2.88	5.54	17.22	3.95	36	<0.001

#### 5.4.9 Analysis of change in SEPC scores over all three time points

A one-way repeated measures analysis of variance (ANOVA) was conducted to evaluate any observed changes in SEPC scores across all three time points of pre-simulation, immediately post-simulation, and six-months post-simulation. This test was conducted for each SEPC subcategory in turn (Table 5.12).

Results demonstrate that there is a significant difference in mean SEPC scores as a result of time, and that this is the case for all three SEPC subcategories.



**Table 5.12 ANOVA results**

	<b>Wilks' Lambda</b>	<b>F</b>	<b>Hypothesis df</b>	<b>Error df</b>	<b>Sig (2-tailed)</b>
<b>Communication Skills</b>	0.156	97.43	2.00	36.00	<0.001
<b>Patient Management</b>	0.227	59.53	2.00	35.00	<0.001
<b>MDT Working</b>	0.222	61.28	2.00	35.00	<0.001

Given the statistically significant results, pairwise comparisons were undertaken to help better understand which of the three time periods were responsible for the most significant changes observed (Table 5.13)

#### 5.4.9.1 Pre-simulation vs immediately post simulation

Results demonstrate there is a significant increase in scores over time for all three subcategories between the pre-simulation and immediately post-simulation time points (all  $p < 0.001$ ).

#### 5.4.9.2 Pre-simulation vs six-months post-simulation

Results also demonstrate a significant increase in SEPC scores across all three subcategories between the pre-simulation and six-month post-simulation time points (all  $p < 0.001$ ).

#### 5.4.9.3 Immediately post-simulation vs six-months post-simulation

Differences in SEPC score between the immediately post simulation and six-months post-simulation time points can be seen for all three subcategories. The mean SEPC score for communication skills falls by 0.87 during these two time points, however this is not significant and cannot be attributed to time ( $p = 1.000$ ). An increase in mean SEPC score is observed for patient management, however this is not significant either (Increase of 3.13,  $p = 0.528$ ).

Interestingly there is a much larger increase observed in mean SEPC score for MDT management of 11.38, and in contrast to the other two sub-categories, this change is statistically significant ( $p = 0.001$ ) and indicated there has been a significant time effect on this score.

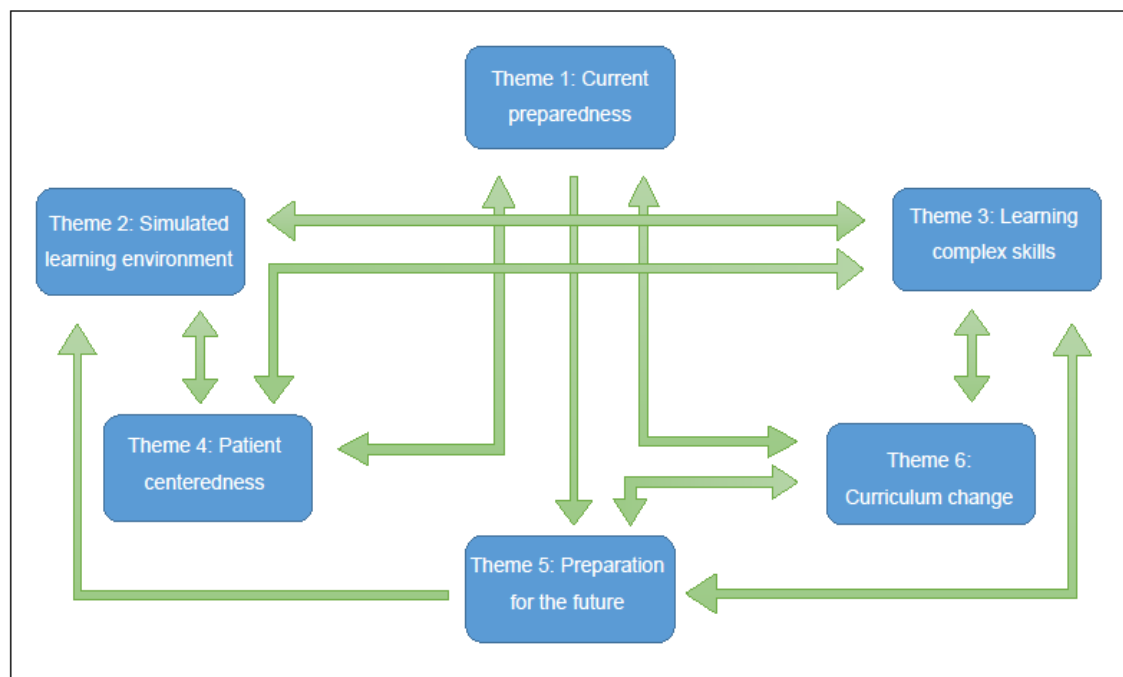
**Table 5.13 Pairwise comparisons for all SEPC domains**

Time (J)	Time (K)	Mean difference (J-K)	Std Error	Sig*	95% CI for difference	
					Lower Bound	Upper Bound
<b>Communication skills</b>						
1	2	-32.10	2.27	<0.001	-37.80	-26.40
	3	-31.24	2.72	<0.001	-38.05	-24.43
2	1	32.10	2.27	<0.001	26.40	37.80
	3	0.87	1.72	1.00	-3.44	5.17
3	1	31.24	2.72	<0.001	24.43	38.05
	2	-0.87	1.72	1.00	-5.17	3.44
<b>Patient management</b>						
1	2	-25.19	2.39	<0.001	-31.20	-19.18
	3	-28.32	2.98	<0.001	-35.79	-20.85
2	1	25.19	2.39	<0.001	19.18	31.20
	3	-3.13	2.27	0.528	-8.83	2.57
3	1	28.32	2.98	<0.001	20.85	35.79
	2	3.13	2.27	0.528	-2.57	8.83
<b>MDT working</b>						
1	2	-18.08	2.00	<0.001	-23.10	-13.06
	3	-29.46	3.03	<0.001	-37.07	-21.86
2	1	18.08	2.00	<0.001	13.06	23.10
	3	-11.38	2.88	0.001	-18.62	-4.15
3	1	29.46	3.03	<0.001	21.86	37.07
	2	11.38	2.88	0.001	4.15	18.62
* Bonferroni adjustment for multiple comparisons						
1 = Pre-simulation / 2 = Immediately post-simulation / 3 = Six-months post-simulation						

## 5.5 Results from qualitative data collection

All 38 students who participated in the simulations also participated in the focus groups. Focus groups consisted of either 4 or 5 students each.

Thematic analysis of focus group transcripts identified six major themes associated with student preparedness and learning through simulation in the context of care of the dying (Figure 5.1). Each theme is discussed in turn, with illustrative quotes from (anonymised) participants.



**Figure 5.1 Identification and interplay of major themes.**

### 5.5.1 Theme 1: Current preparedness

One of the key areas of exploration in this study was how prepared students felt in relation to caring for a dying person and their family, and as such this was one of the key areas focussed on within the topic guides with overlap seen with several other themes. Throughout the focus groups participants referred to their current lack of preparedness in a direct way by reflecting on how they felt going into the simulations, but also how they would imagine they felt had they not experienced the simulations:

*I think it's hard going into one where you have to have those conversations with not having seen it in real life before. [Student K]*

*It would be so terrifying if you saw this for the first time as an F1 on call on a night shift by yourself and you weren't here and that was the first time you'd ever seen anything like that which I know is definitely gonna happen. [Student Z]*

It was also apparent that participants were not always aware of their lack of preparedness, as certain statements reflected a general lack of interaction with dying patients:

*It would be difficult to have to be more patient centred because obviously the patient is in the last minutes or hours so you can't really talk to them any more than you do when you say 'hello' and examine them and things because they are unconscious and you can't really include them any more than that. [Student D]*

As part of the topic guides, students were specifically asked whether they felt the current curriculum prepares them to care for dying patients and their families. Overall opinions were that the undergraduate curriculum does not prepare them well enough:

*I think we're taught a little bit at the start of um med school but then it kind of we don't get any more training on it and then you're just kind of trapped in the deep end [Student GG]*

For those students who had completed their hospice placements prior to their allocated simulation day, opinions suggested a complimentary effect existed between the placements and the simulations – whilst making clear that the simulations should not be considered a complete substitute for either hospice placements or lectures:

*I though the palliative care I can't remember two or three days I thought that was really good and informative um but that was more on the medical side of dying and like the drugs you use and how to prescribe them etcetera [Student DD]*

*I think it is lacking something like this to be honest I think we've had a fair amount of lectures especially on our hospice days um but I think for me I thought I took a lot from the lectures but this was a totally different experience that I think added a lot more than lectures alone [Student JJ]*

Some students recognised the potential self-selecting nature of the group and

used this to compare their own level of preparedness to those who they felt would not have volunteered to take part in such a study:

*I also think like one of the things that would be good if everybody can do this because we're all quite emotionally intelligent in this room ((several laughs)) you know but like there are people who aren't ((muttering comment in overlap)) no but like there are people who wouldn't know what to do. [Student G]*

In addition, some students felt other students would not be well prepared for the emotional impact of the simulations:

*The advantage was we chose to do it whereas if you put it in the curriculum some people might find it really difficult and it might bring emotional feelings that they don't really want. [Student EE]*

Within this theme came the idea of managing one's own expectations, and several students recognised the need to prepare how to manage the expectations of others. Students felt that having the actor in the scenario helped them to focus their conversation, and be guided by what it was the actor wanted to get out of the consultation. Students felt that knowing what not to say was equally as important as knowing what to say, and that the simulations were a way to begin preparing for this:

*I think it was also good to learn how to manage relatives' expectations I think with my scenario in particular it was good to kind of (.) try and figure out how I need to approach such conversations and what to say and what not to say [Student P]*

For others, the simulations were a way of benchmarking where they were at as individuals in terms of their ability to cope with such a stressful situation should it arise in the future (sharing links with Theme 5):

*I felt this experience has been really helpful just to kind of ascertain my level in dealing with similar situations. [Student T]*

Whilst the simulations were almost unanimously well-received, one student (Student L) commented on their personal experience with respect to how the simulations worked for them:

*I think it's difficult to say that yeah you feel good about it or confident because I don't particularly want to do it again (Student L)*

Such a response may be due to continued low-confidence with regards to providing care to the dying, or in participating in simulations in general.

#### 5.5.2 Theme 2: Simulated learning environment

This theme consisted of two subthemes, reality of scenarios and reality of the simulated environment, each of which will be described below.

One of the key areas of interest to the primary researcher was in relation to the reality of the scenarios and the simulated environment. The simulated scenarios had been based on real-life clinical encounters that the primary researcher had been involved in, and had been developed and refined based on the feedback received from similar scenarios used in the previously mentioned feasibility study. Overall students found the scenarios to be realistic especially when compared to their observations of care of the dying on clinical placement:

*I was on an AMU ward round in year three and there was a situation that was like this so it proves it's realistic and you know the patient was in a side room luckily so that's really realistic. [Student U]*

For those students with no prior experience of caring for the dying, thoughts centred around how this simulation may reflect their future encounters in the post-graduate setting. It appeared to offer new insights to them and there was a strong association with both Themes 3 and 5 where students had an appreciation that complex skills will need to be learnt to enable them to carry out their responsibilities as future qualified doctors:

*I think it was a really realistic set up of things that we will probably encounter in everyday lives as a junior doctor [Student X]*

Despite efforts to maintain realism, conversation in the focus groups centred around the fact that as it was a simulated learning environment it could never be fully realistic. Many students felt the setting was similar to an Objective Structured

Clinical Examination (OSCE), and as a result they went into their scenario with the mind-set that they had to achieve certain tasks in order to 'pass' the scenario. Others commented on the fact that the mannequin detracted from reality, acknowledging that they did not always know how to interact with the mannequin especially as it was unconscious. Some students felt that because the simulated patient was unconscious it didn't really matter that they were represented by a mannequin, whereas for others the mannequin was seen as one of the disadvantages of the simulations:

*It's as realistic as it can be but the main disadvantage is that it's not real and part of you will always be aware of the fact that it's not real. [Student H]*

*Well it's a dummy so that's an obvious disadvantage. [Student C]*

In contrast to the above this limitation on reality appeared provided some students with a certain reassurance, as it afforded them the opportunity to make mistakes in a safe environment and learn from them without causing harm to anyone:

*Having the comfort of knowing this wasn't actually a real life scenario where a patient was dying in front of me and I might have said something wrong or done something wrong. [Student Q]*

The simulation room had been set up to mimic that of a hospital side room, and some students commented on how small the room felt. This was an interesting observation as the simulation room is a larger than average hospital side room and may be reflective of their lack of experience on the wards. Other students felt it was not possible for them to comment on how realistic the simulations were given they had not encountered any dying patients in their studies so far and as such had nothing to compare to:

*I've never been in a situation like that on placement or in the hospice or anything like that so I can't really compare the simulation to um being on the wards for me that was a completely new experience. [Student L]*

### 5.5.3 Theme 3: Learning complex skills

With the exception of Theme 1, this theme overlapped with all other themes and can be sub-divided into three subthemes of peer learning and feedback, communication with relatives and communicating with simulated patient.

#### 5.5.3.1 Peer learning and feedback

Students were overwhelmingly positive in the focus groups when it came to the value of learning from their peers, and receiving peer feedback on their performance. Whilst some students felt more nervous knowing they were being watched by their peers, they seemed to forget this was happening when they were performing their individual scenarios. As explained in the methodology, the adjacent observation room was divided by a one-way window which allowed peers to look into the simulation room, but did not allow the simulating student or actor to be distracted by observers. Students commented on the ability to observe others and learn from new communication techniques and body language that potentially differed from their own:

*I find it really nice to see how others would react and act in the similar situations I've definitely learnt like useful phrases that I can use in the future from other people as well [Student T]*

Furthermore, as the simulations grouped students together in a random way, some enjoyed the fact that they got to learn from fellow students who they would not normally interact with either on a social or academic level. This seemed to add to the richness of peer learning:

*learning from each other and in particular learning from people that you don't necessarily practice with at doing OSCE's (Objective Structured Clinical Examinations) or anything else. [Student AA]*

Much like the reassurance students felt in relation to theme 2, here students were reassured with respect to their own skills and abilities having watched their peers work in a similar way to them. There was a certain realisation that the way they worked and communicated was not wildly different from others at their level:



*when you watch other people do it and they say the same thing you're like well actually what you did was really good so maybe what I did was actually alright [Student N]*

If there was to be any criticism from observation, it was that some students felt that by just copying others would mean you would not learn how to do things for yourself:

*But then is that a disadvantage at the same time cos you're just copying what they're doing and you can't do that in real life. [Student L]*

#### 5.5.3.2 Communicating with the relative

The main feature within all the scenarios was the requirement for the student to communicate with the relative. The relative had certain questions to ask the student, and was set to reflect the type of questions they would be asked a junior doctor in a similar situation. Students commented on how they felt having to communicate to a relative in such an emotive situation:

*Yeah I feel better about talking to patient's families as well rather than just the patients themselves but try and understand all the different possible not all of the different possible but a lot of the different possible emotions that people will be going through and how they're expressed and how to deal with those in the clinical situation. [Student K]*

*I thought this was better in terms of like communication exercise and to talk with the families et cetera which is yeah I think what people want are worried about when it comes to palliative care. [Student DD]*

Whilst there were no objective measurements taken to score how well students communicated with the relative in their scenario, there was opportunity for feedback between each scenario. During this time the actor was able to provide constructive and focussed feedback about how they felt the students performed, with focus on any nuances within the particular scenario that were felt to have been handled well. Students coveted this feedback, commenting that it helped them appreciate areas of good practice as well as identify areas where they felt their undergraduate training was lacking:

*I think we're trained very well in how to approach talking about cancer like diagnosis of cancer at least in my like two weeks of the oncology rotation week we kind of talked about how we would break bad news and had a whole session on like how to do it but talking about dying is completely different we don't have that training I think [Student O]*

#### 5.5.3.3 Communicating with the patient

Although this subcategory shares a lot with Theme 4, it is worthy of mention here as this was a skill many students did not feel able to engage with. Although a lack of reality may have influenced communication as described within Theme 1, students appeared unaware that communicating with the dying patient was likely to be important. Several students commented that as the patient was unconscious they assumed they would be able to hear what the student was saying:

*It would be difficult to have to be more patient centred because obviously the patient is in the last minutes or hours so you can't really talk to them any more than you do when you say 'hello' and examine them and things because they are unconscious and you can't really include them any more than that [Student D]*

For others it became apparent they did not know how to communicate with the dying and this was something that was brought up during the feedback session and will be discussed later in this chapter. On a few occasions students did involve the patient more within the consultation, talking to them throughout their examination and explaining what they were doing.

Students did recognise that this was a skill that required exposure and practice, rather than be something the learnt from a text book:

*Communication skills you can't like learn them almost it's not something you can just look in a book it's sort of a practice of some people are just naturally quite good at it or some people lack a bit more confidence [Student GG]*

#### 5.5.4 Theme 4: Patient centeredness

As seen in the focus group topic guides, students were asked to identify some advantages and disadvantages of the simulations. Several students commented on the fact the simulations were much more focussed on the relative than the

patient. This theme shares links with the diminished reality evidenced within Theme 2, as well as element of complex skill acquisition within Theme 3:

*If there were scenarios like telling a person that they are dying, then that would be really useful and that could be would be more patient focussed which would be good [Student D]*

Some students felt having the relative acted as a bit of a distraction in that they felt obliged to focus their attention on the relative and away from the patient. Students suggested that having different relative or no relative at all in some scenarios may have improved variation within the simulation:

*Having scenarios that were completely different someone who wasn't unconscious every time or had a different disease or a different relative or maybe like no relatives or something just different in each one cos I know the first person when they died sort of threw you off but in my station there wasn't really anything to sort of throw me off particularly [Student K]*

The perceived lack of patient focus was seen as a real disadvantage within the simulations, with the suggestion that more patient involvement would add to the realism of any future simulations. It was suggested by some that having an actor playing the patient may have helped achieve this, because for some there was a perception these simulations contained almost no patient involvement whatsoever and offered suggestions for improvement:

*I think the only thing that would have made it more realistic would be having more patient input I just think it really lacked that... often you would initially ask just the patient what they want you would focus on them first but I think it just missed that entirely [Student LL]*

Others disagreed and recognised the challenges of having an actor play the role of an unconscious dying patient, surmising that there may not be much to gain from this:

*But then I guess even if it was a human patient they wouldn't be dying so I don't know if you were to assess them they would just be you'd still have to kind of like pretend that you were hearing so I'm not sure and especially if the patient is supposed to be unconscious I'm not sure what more you would gain having a human there [Student II]*

### 5.5.5 Theme 5: Preparation for the future

The overriding theme running throughout the focus groups was the aspiration amongst the students to be as well prepared as possible for future encounters with dying patients. They were keen to learn new skills and be exposed to more scenarios as they unanimously recognised that this is something they will have to do within days or weeks of starting their first jobs as newly qualified doctors. Students believed that participating in the simulations as individuals would be preferential to doing it in pairs, recognising that they will need to be able to do this as qualified doctors in an on-call situation. Following the simulations there appeared to be a realisation amongst the students with respect to their future jobs, almost as if the simulations opened their eyes to the sort of reality they are likely to face in clinical practice. For some this reality was stark:

*the real world is coming and we are going to be doctors one day... having a glimpse into that world and being like oh crap we're gonna have so much worse than this [Student G]*

For others, a more pragmatic outlook was adopted:

*I think the advantages are well the main one for me it's stimulated me to think about that you know in a year or a couple of years' time that this will actually be reality and I don't think I really thought about that before this that I will be at some point with someone when they die and I hadn't I don't you don't really think about it when you're at med school [Student L].*

However, some students also recognised the importance of doing your best to get things right when faced with a real dying patient, understanding that there will not be any second chances if mistakes are made:

*I think here I would just way rather mess up here than and have as many practices here to reduce the chance of messing up in real life cos that would be so much worse (Student M)*

Whilst more students were in agreement that the simulations added to their preparation for future encounters, there was an element of acceptance that the simulations would not be the answer to all end of life care teaching:

*you wouldn't necessarily be able to know how it would feel to be in that situation actually having the conversation um and I think that's the only way to prepare really [Student D]*

*It's difficult to say oh yea well I could do this next time when like all five situations were completely different so having done one doesn't mean I am necessarily any better prepared to deal with someone who is going to sit there and blame me for their death or someone whose gonna start wailing [Student N]*

Despite any shortcomings of the simulations, students appeared grateful for the opportunity to learn more about how to care for dying patients and their families, with a palpable desire continuously improve their skills by 'having another go'. Many participating students appeared to have this drive to ensure they can do their jobs better, and recognised that learning from mistakes now would facilitate this in the future:

*You wanna just do a better job and then I feel like you learn from your own mistakes [Student F]*

*You realise what you would do next time and you know what you would change I think that's really useful to do [Student II]*

Students felt the key to preparation was practice, and these simulations gave them the environment in which to do exactly that:

*I think doing it and running through different scenarios makes me feel a little bit more less panicky I guess and not flipping around going 'I don't know what I'm doing' and actually just go like 'right let me just think clearly here' [Student I]*

#### 5.5.6 Theme 6: Curriculum change

The final theme centred around what the students felt needed to change in the current undergraduate curriculum with respect to teaching on how to care for a dying patient. Many felt the simulations would be a valuable addition to current palliative care teaching within the medical school, to compliment both the lectures and hospice placements.

Many students compared these simulations to those that already exist in other areas of the undergraduate curriculum, for example the dementia simulation all students participate in as part of their elderly care rotation. The dementia

simulation appeared to be popular with students, helping them to deal with complex communication skills:

*Like an afternoon kind of like we had with the dementia sim in third year something like that would be quite useful and relevant [Student G]*

Irrespective of individual comments about confidence to perform in the simulations (as described in Theme 1), there was not a single student who felt the care of the dying simulations wouldn't be valuable within the current undergraduate curriculum. Students were specifically asked in the focus groups where they thought the simulations would be best placed within the curriculum, with opinions divided within almost every focus group. The most popular answer was to place the simulations in the 4<sup>th</sup> year as part of the palliative care rotations, however many students felt that it would be better placed right at the end of their training in the two weeks of 'preparation for practice' that is offered to newly qualified doctors prior to starting their first jobs. Whilst the majority agreed it would not be suitable any earlier than 4<sup>th</sup> year (as by that time students will have developed reasonable communications skill to be able to get the most value out of the simulations), a few students felt placing it in the first or second year may work best. This often led to debate amongst the students in the group:

*Student J: I the only thing I would say in terms of when you would put it I don't know if it would I'd like I'd go earlier as early as the end of year 2,*

*Student I: Really?*

*Student J: Beginning of year three*

*Student H: You need to have some clinical skills though*

*Student J: Not in year two but I mean in the third year at some point*

*Student G: But we go through too much stuff in the third year*

*Student J: I know that's the only problem*

*Student 1: And plus once you've done year three OSCE's you are a bit more smooth like the base is there you know*

Some students wondered whether the structure of the simulations may be amenable to change, with the suggestion that each simulation could follow a short teaching session on the subject matter being simulated, for example, spiritual care in the dying patient, with the idea that the newly acquired knowledge could then be applied straight away.

## **5.6 Discussion**

All 38 students completed their simulation scenarios, and no single student appeared to have been distressed by the simulations. As described in chapter 3 (methodology), the simulations were to last a total of 8 minutes each, or end when the student felt they had achieved all that they could. Not all the simulations ran to 8 minutes as some scenarios came to a natural close a little earlier in some cases. However, at no point did any scenario appear to end prematurely without the main focus having been achieved.

When looking at the three domains of the SEPC in isolation, results demonstrate that confidence in communication skills, patient management, and MDT working have all increased as a result of the simulations. Although interpretation of findings must take into account the limitations of this study as described later in this chapter, the results support the first hypothesis for study 3 as stated in Chapter 1.

Students' mean SEPC scores at the pre-simulation time-point were situated approximately one-third along the scale for all three sub-categories. This was the baseline confidence seen in our study participants and shares findings from similar studies included within the earlier systematic review. Although these studies used several different scales to measure baseline confidence (including the SEPC scale), the majority of students scored in the lower half of each scale indicating a low level of confidence in relation to the management of a dying patient. <sup>(97, 99, 100, 102-104)</sup> Published research has found similar results in relation to communication with dying patients, with studies reporting a baseline confidence of less than 50%. <sup>(74, 99-103)</sup>

Although many of the studies did not specifically look at MDT working, those that report the application of the SEPC scale were able to report on this domain and demonstrated that baseline confidence centred around or below the 50% point of the scale <sup>(98, 99, 103)</sup> which is in-keeping with our findings.

Thematic analysis identified six major themes from focus group data. As demonstrated in Figure 5.1 a complex interplay exists between all six themes, with each theme overlapping with at least two other themes

In particular students' perception of their current preparedness to care for a dying patient (Theme 1) linked closely with both their views on the limitations pertaining to patient centeredness within the simulations (Theme 4), their awareness of the need for further preparation for future encounters with dying patients (Theme 5), and suggested changes to the current undergraduate curriculum in order to address preparedness (Theme 6).

For many students there was a recognition that had they not participated in the simulations, it was possible they may never be involved in the care of a dying patient (simulated or otherwise) as an undergraduate. The thought of this in itself appeared to create anxiety within the students. As a result, there was almost a gratefulness exhibited amongst the students for the exposure afforded to them by the simulations, giving them an understanding of what it may feel like when they have the true responsibility of caring for someone who is dying. This is an important finding as it highlights how the students feel, with many stating they had not experienced anything like this before. This shares findings with the outcomes of published reports that conclude students desire more exposure to end of life and care of the dying teaching at undergraduate level.<sup>(12, 19)</sup>

It is important not to do a disservice to the undergraduate curriculum at BSMS when discussing student preparedness. Students in the study reported positive feedback in relation to the structure of the palliative care teaching, and in particular those who had completed their hospice placements found them very rewarding in terms of exposure to palliative care patients. However, it became apparent from analysis of focus group data that despite experiences on placement, students are still finding there is a lack of exposure to actively dying patients as it is not guaranteed that there will be such a patient being cared for in the hospice at the time students are in attendance.



Studies looking at the structure and content of palliative care teaching in the UK state that educators are trying to address medical student fears about death and dying. Such fears include the first encounter with a dying patient, what that may look like, and how different it may be from their expectations. <sup>(157)</sup> However, given the heterogeneity between medical school curricula, it will be difficult for institutions to ensure that students will all have experienced some exposure to a dying patient by the end of training. Simulation would help to address this by providing a consistent approach to teaching in this area and could ensure that all new graduates will have encountered specific hands-on teaching on the care of a dying patient and their family.

More in-depth discussion pertaining to study 3 will be presented in chapter 7.

### **5.7 Strengths and limitations**

Prior to this study there has been little research looking at how to address the ongoing problem of low confidence and preparedness amongst junior doctors in caring for dying patients, and even less research exploring the use of simulation to specifically see whether it can be used to teach medical students how to care for an actively dying patient.

This study also adds to the growing body of literature describing the adoption of in-simulation patient death as part of teaching, and to our knowledge is the first study using mid-scenario patient death as part of an 'expected death' scenario. Simulations exposed students to an area of palliative care they seldom experience in undergraduate training, with almost no similar experiences reported by students on clinical placement.

The development of this simulated study was based upon a published and peer reviewed feasibility study, and as such had been refined and adapted based on feedback from both participating students and experts. This benefitted the study simulations as feedback was used to enhance the fidelity within the scenarios, improve scenario timing, and adapt student and actor scripts to maintain the complexity of the interaction between individuals within each scenario without over-complicating the task being asked of the student.

The decision to use the SEPC questionnaire to collect self-efficacy data was based on the outcome of the published and peer-reviewed systematic review (Chapter 2), with justification for its use based on the fact it is one of the only tools

validated for use in medical undergraduates. This adds to the credibility of data collection, as opposed to using another published tool that does not possess the same level of validation.

Despite initial challenges of VAS scale measurement described earlier in this chapter, independent measurement of scores demonstrated a high level of inter-rater agreement. Added to this is the fact that 100% of questionnaires were returned for all study participants at all three time points, and within these the level of missing data was low. For a small number of the emailed questionnaires, some individual students failed to document their memorable data (word/symbol). It was therefore necessary to return these to the individuals with a request for them to add this information and email it back. Upon return the questionnaire was then saved as a separate document and the email deleted in order to maintain anonymity.

This study is not without limitations, and these will serve to strengthen any future studies that are carried out using similar simulation techniques.

The self-selecting nature of study participants is acknowledged by both the research team and by the participating students who highlighted this limitation within focus group discussion. Although the findings of study 3 were found to be similar to those of studies reporting the use of simulation in other healthcare settings, the influence of non-response bias must be considered here. As participation in the simulation study was voluntary, it is probable that those who volunteered were likely to be more interested in simulated learning as well as having an interest in learning more about palliative medicine, end of life care, and care of the dying. As described earlier, every student in the 4<sup>th</sup> year cohort (n=123) was contacted in order to achieve the 40-participant target. This means that at the invitation stage of the study process 83 students declined to participate (either through active declination or non-response). It is important to recognise that had some of these non-participants taken part, the results obtained from the study may well have been different. Whilst we did not gather data to compare differences between the participatory and non-participatory groups, it would have been interesting to identify whether particular characteristics (for example, age, gender identity, ethnicity, religious affiliation, previous personal or professional experience of death and dying) existed between these groups which may have influenced a decision to participate, and contributed to non-response bias.

Taking into account this potential for non-response bias, the generalisability of these results will rightly be questioned. The final study population represented one-third of the year 4 cohort, and therefore may not be representative of the entire cohort. If simulations were to become a compulsory part of the undergraduate curriculum, study results from whole year groups would mitigate the risk of non-response bias. Additionally, results of future study could be compared to those of study 3 to determine whether non-response bias was likely to have influenced results obtained.

Whilst this study measured confidence at three time points, it is acknowledged that discussions around preparedness only took place in the post-simulation focus groups, therefore it was not possible to comment on students' preparedness at the six-month period of data collection, and would have added richness to the data. However, unlike confidence which is described in this study as a measure of one's ability to perform a task, the definition of preparedness is described earlier to be a reflection of what the medical school have offered to students in terms of teaching on care of the dying patient. As the simulations left the students feeling better prepared in the post-simulation setting, this preparedness would likely remain the same (as you can't retract the knowledge or experience students gained from the simulations). However, it is acknowledged that students may report 'feeling' less prepared as they near their first jobs as junior doctors.

There was a lack of control group in this study, and it may have been prudent to ask non-participating students to complete the study SEPC questionnaires from which comparisons could be made with the study group. Undertaking the ANOVA analysis within this study did look to see whether changes in confidence were the result of time alone within our study group, and it would have been interesting to see how non-participating students' confidence changed as a result of time in comparison.

The final, but arguably the biggest limitation of this study are the practical and financial implications of implementing such a teaching resource at undergraduate level. Practical implications include where to fit the simulations within an already packed timetable. Whilst it has been explained earlier that simulations have not been designed as a clinical placement substitute, coordinators of undergraduate teaching could use the simulations as an adjunct and consider using them to

replace some of the didactic lectures with their current curriculum. Specific content can then be added into the scenarios to tailor the learning to ensure alignment with GMC and APM recommended outcomes. Simulations could also be viewed as a way to supplement (not replace) clinical placements in those situations where increasing pressure on placements means students will be spending less time in hospices or on the wards. It would be important to ensure that if this does happen, all students get the opportunity to participate in simulations in the interests of fairness and equality in teaching provision.

Whilst financial implications are always a concern, especially as simulation is a relatively costly resource when compared to didactic lectures, what we have seen is significant detrimental effects of poor undergraduate preparedness at FY1 level. As such significant change and investment in undergraduate preparation will be essential to address this situation. Most medical schools have already invested in simulation suites and are often not always in use. Given that significant time and money has already been spent on acquiring simulation resources for students, a strong argument exists in ensuring they are being used to their full potential.

## **5.8 Conclusion**

This mixed methods study has been undertaken to determine whether simulation can improve confidence and preparedness of medical students to care for dying patients and their families. This study has found low baseline confidence amongst students with respect to caring for the dying, and echo findings already reported in the literature. Equally, the perceived lack of preparation at undergraduate level also shares similar findings within results of published studies. However, this study has taken this a step further and adds significantly to what is already known. The quantitative component has demonstrated that statistically significant improvements in medical student confidence can be achieved as a result of using simulation to teach students the complexities of caring for a dying patient and their family. Not only does confidence increase, but it is sustained over a six-month time period. This is the first UK study that has demonstrated this in the context of medical students. Qualitative data identified six themes related to how much students believe their current curriculum prepares them to care for the dying, identifying current shortcomings within the curriculum and clinical placement. Students expressed

a strong desire for further teaching in this area and found the simulations afforded them the opportunities and exposure they are lacking on the wards. Students were unanimous in advocating the incorporation of the simulated teaching on care of the dying into the undergraduate curriculum.

## **Chapter 6: Patient and Public Engagement**

### **6.1 Introduction**

One of the important features of any research is the representation of the patient and public voice. It has been accepted that active involvement of healthcare service users in the research process leads to development of research of greater quality and relevance.<sup>(158, 159)</sup> Whilst more recent studies looking at the impact of Patient and Public Engagement (PPE) on research outcomes has suggested this association is weak and fraught with challenges, the prevailing message is that incorporation of PPE into any research serves to enhance rather than detract from outcomes overall.<sup>(160)</sup>

In order to validate the findings and to incorporate the patient and public's perspective into future implementation of curriculum recommendations, recently bereaved relatives were asked about their views with regards to the teaching of medical students about death and dying, and asked to share any personal experiences of bedside teaching they may have observed whilst visiting their dying relative.

### **6.2 Aim**

To gather and explore the experience and opinions of recently bereaved relatives with respect to teaching medical students and junior doctors how to care for a dying patient.

### **6.3 Method**

This was primarily a consultation rather than a research exercise, therefore, following discussion with the research team, the medical director of a local hospice (who also facilitated one of the study simulations) was contacted by email to ask permission to arrange to speak with a small group of recently bereaved relatives who had accessed palliative care or a bereavement service through their hospice. Details of the level of involvement as well as the aims of the meeting were explained in a covering letter (Appendix M) signed by the primary researcher and countersigned by the main research supervisors. It was explained that there would be no audio-visual recording of any meeting that took place, but that field-notes would be written by the primary researcher to capture opinions, thoughts and experiences of the public contributors. Individual contributors would

remain anonymous within the field-notes. Both the primary researcher and medical director felt the hospice bereavement service would be the most appropriate team to identify and contact recently bereaved individuals who they felt may be willing to contribute. In total three individuals volunteered to participate in the PPE exercise and a mutually convenient date was set where all three contributors could meet with the primary researcher at the hospice for the group discussion to take place. This hospice represented the most convenient meeting point for all three public contributors in terms of location, familiarity, parking availability and public transport facilities. Additionally, formal bereavement support was available at the hospice should any of the contributors wish to access it on the day given the emotive nature of the subject matter.

A topic guide to help steer the conversation during the PPE meeting was developed (Appendix N). Individuals were informed of the purpose of the meeting. In particular, it was explained that the group was voluntary and that people were free to withdraw their involvement at any time without the need to offer a reason for doing so. It was explained that people were free to discuss as much or as little as they liked during the session, and that their responses would be translated into general themes from the discussion with anonymity of individuals within field notes and documentation within the thesis. It would therefore not be possible to remove any individual comments at a later date as they were anonymised. Finally, individuals were informed that the PPE session was not a bereavement session and that it would not intend to infringe any formal bereavement services individuals may be receiving at that time. If during the PPE process individuals felt they would benefit from the support of formal bereavement services, the primary researcher was able to refer them back to the hospice bereavement team.

After the session had been completed the primary researcher typed the field-notes and agreed to email a draft copy to the contributors for their comments on accuracy, and whether they wished for anything to be amended.

Finally, the primary researcher made the decision not to inform the contributors that simulation had been used as part of the study within the medical doctorate until the end of the session. This was important as to have done so at the start may have risked influencing discussion responses from the group. The purpose of the PPE session was not to ask their opinion about whether simulation would

be a teaching option but to gather their own personal experiences of teaching in the context of their dying relative.

#### **6.4 Ethical considerations**

Recently bereaved relatives were involved in the PPE process to provide their personal experience and insight in order for the primary researcher to better understand what views exist with regards to the teaching of medical students at the bedside of a dying patient. When members of the public are involved in PPE they are acting as specialist advisors in that they are providing individual opinions and experience. As such formal ethical approval for their involvement was not required.<sup>(161)</sup>

#### **6.5 Incentive for contribution**

As a thank you for their voluntary contribution a voucher was provided to all three public contributors to cover the cost of lunch in the hospice restaurant, which they were able to use after the session had ended.

#### **6.6 Results of discussions**

The PPE session took place on 20<sup>th</sup> February 2020 in the morning, with all three public contributors in attendance. Although the session was booked for 1 hour, each contributor engaged in enthusiastic discussion for over 2 hours.

##### **6.6.1 Main subject themes**

###### **6.6.1.1 Experience within the hospital setting**

Observation was that of junior doctors learning from consultants, perhaps as part of a teaching ward round. However, it was not always made clear to patients and relatives which individuals were junior doctors and which were medical students.

Whilst some individuals experienced care with some great doctors, there were also some examples of very poor communication and attitudes from senior consultants. In some cases, patients and relatives were made to feel unwelcome in the hospital given the realisation that the patient was dying. They were made to feel their relative should be being cared for somewhere else. On one occasion a consultant brought several students around the bedside without seeking permission from the patient. It was strongly felt by the contributors that this demonstrated a lack of respect for the patient and as such was viewed as representing poor patient care. Public contributors were concerned that this display of disrespect from a senior member of healthcare staff had the potential



to negatively influence students as they would look to their consultant as a role model.

Overall there was no great sense of the presence of medical students on the wards, and certainly it was not made explicit that they were at the bedside of dying patients.

#### 6.6.1.2 Experience within the hospice setting

Some contributors recognised that their encounter with death was only the first or second time in their lives they had experienced such an event.

They found their experience in the hospice completely different and more positive in comparison to that in the hospital in terms of care of the patients and relatives. However, even in the hospice there was a limited experience of seeing medical students present, speaking with patients, or speaking with relatives.

#### 6.6.2 Opinions regarding teaching medical students how to care for dying patients and their relatives.

##### 6.6.2.1 Number of students

The overall view from the group was the fewer students around the bedside the better. Some had witnessed seeing multiple students at the bedside and found this to be a negative experience. The group felt this could be overwhelming for all concerned, particularly the patient. However, they also felt that students should be allowed to learn from the bedside.

##### 6.6.2.2 Asking permission

Contributors felt it imperative that permission to teach students at the bedside is sought first. The purpose of any medical student visiting should be explained to the patient, or the relative if the patient is unconscious. It needs to be made clear whether the patient will be physically examined, whether the student will be only observing or taking a more active role at the bedside.

##### 6.6.2.3 Role of the student

The general feeling was that taking an active role would be seen as a positive thing, as it would demonstrate attention and facilitate learning. Merely observing would potentially suggest they are in the background and risk not being fully engaged.

#### 6.6.2.4 Awareness of dying

It is not always apparent when someone is dying. Doctors can often be unsure themselves when someone is dying, and often make errors when giving a prognosis. Some of the contributors explained that they themselves did not recognise when their loved ones were dying and felt this reflected their own lack of experience in this area. Such views and experiences add weight to the argument for increased student exposure to dying patients, as this is felt to be the best way in which students and future doctors can learn how to recognise and diagnose dying in their patients.

#### 6.6.2.5 Benefits of bedside learning

The group agreed that the best way to learn is to be at the bedside as it enables students to learn how to interact with conscious patients, but also develop skills in the assessment of an unconscious patient. They can develop the skill of recognising when someone is in pain by observing breathing patterns, assess how the patient looks and observe skin changes. Contributors felt strongly that only so much can be learnt from lectures, and that the older style of bedside teaching is felt to be one of the best ways in which to teach students.

#### 6.6.3 Alternative teaching methods

Contributors had much to say about how else students could be taught how to care for the dying patient and their families, and suggested alternative teaching methods as seen below.

##### 6.6.3.1 Simulation

Other ways to teach could include simulation. One contributor's initial thoughts were that using simulation in the care of the dying seemed a little odd, however they drew from their own experience of life support training using Resusci-Annie manikins and actually felt that simulation could be used in this setting. In particular, it was felt that simulations ought to have an actor playing an angry, distraught, confused relative etc. to foster reality.

In addition, it was suggested that to make things even more realistic, one should consider using background noises to simulate those you would hear on the wards, voices, beeps from machines and so on. It may also be worth thinking about introducing a ward-based smell as well if it were possible.

It was postulated whether the students themselves could take turns to be the dying patient, whether this would be of value to them.

#### 6.6.3.2 Use of film and television

Discussion around different films that may confer educational value, in particular learning that every patient has had their own journey, that a lot has already happened before they see you. Students and educators should be aware of this and respect this.

#### 6.6.3.3 Linking medical students and junior doctors to a lead nurse

Creating this link may teach students about nursing intuition, but also they can learn from a healthcare professional who will have had much more experience looking after dying patients and could offer much to the students/junior doctor if it was practical to do so.

### **6.7 Summary of PPE session**

This ability to speak with recently bereaved relatives was a humbling, emotional and thought provoking experience which generated much discussion within the group. Contributors spoke freely and shared some of their most sensitive experiences about one of the most difficult times in their lives. What was clear from the group was that they felt medical students should be taught how to care for the dying, and that bedside teaching was an appropriate way of doing this providing certain rules were followed, namely informing the patient and relative when students were present and explaining the role they would play. This was felt to be the best way to demonstrate respect to the patient, and exhibited an example of good patient care to which students should aspire. One of the key areas that provoked the most emotion during discussion centred around role-modelling from senior medical staff. Some contributors had, on a minority of occasions, experienced a general lack of empathy and respect from those clinicians who did not appear to feel able to provide compassionate care and instead conveyed the message that the patient had no place being on their ward or in their department.

Whilst contributors were not aware that simulations had been used as part of the study, they did mention simulation as an alternative teaching method in care of the dying patient. After initial questioning about how simulation might fit, further discussion led to group members identifying other examples of where student

teaching used simulation with positive outcomes (e.g. Cardio-Pulmonary Resuscitation). The use of film was suggested as a way of impressing upon students that patients and relatives will have been on an individual journey prior to seeing students for the first time. Contributors felt an apprentice-style of learning would allow students to learn from individuals with greater experience and interest. Ultimately the group felt that there would be no substitute for bedside teaching.

## **6.8 Key messages**

- Bedside teaching is seen as an acceptable way to teach students how to care for the dying.
- Relatives are not averse to students being taught at the bedside, providing that the patient and relative are afforded due respect through the use of good communication
- Simulation, the use of film, and an apprenticeship-style of learning may be alternatives ways in which students could learn how to care for a dying patient, but should not be seen as a substitute for traditional bedside teaching.

## **Chapter 7: Discussion**

Whilst each study chapter has concluded with a discussion of its main findings, chapter 7 provides an overview of the findings in their entirety. This chapter will explore how study findings relate to data within published literature and will argue the case for using simulation in the teaching of care of the dying patient in the context of medical education theory. It will conclude by exploring the unexpected findings from study 3.

### **7.1 Discussion of quantitative data findings**

Whilst the main aims of this thesis sought to identify a change in confidence as a result of simulated teaching on care of the dying, it is important to discuss why a low level of pre-simulation confidence is seen within the medical student population. Results from the systematic review (Chapter 2) literature suggests that low confidence to care for the dying tends to be the result of a lack of experience and exposure to dying patients in undergraduate training. Students appear more confident discussing the pharmacology around complex symptom control such as pain and nausea management having received many lectures on drug pharmacology, but far less confident when it comes to discussing clinically assisted hydration and nutrition in dying patients. This lack of experience is attributed to the poor development of palliative medicine teaching within undergraduate curricula, or a complete failure to integrate it altogether. A recent systematic review of undergraduate palliative care curricula has concluded that greater consistency is now being seen with teaching provision both in the UK and USA. This is particularly with respect to symptom control and communication skills, with a wider variety of teaching modalities adopted by medical schools to deliver this teaching.<sup>(51)</sup> However, whilst consistency may be improving, there remains a lack of clarity regarding the organisation of palliative care training at undergraduate level.<sup>(162)</sup> The funding of undergraduate palliative and end of life care teaching can be seen to create yet a further potential barrier to education given that undergraduate (and postgraduate) hospice placements are excluded from the national medical undergraduate tariff. As a result, hospice placement funding has to be agreed locally between the university and hospice, adding an

extra layer of complexity and time commitment to the organisation of such teaching.<sup>(163)</sup>

The students in study 3 were all in their 4<sup>th</sup> year of training, and some will have already completed their palliative care placements within local hospices. For others this was yet to come. All simulations were conducted over a 2-month time period, and as such the differences between the numbers of students that had undertaken their hospice placements at the start of the study compared to those at the end would have been kept to a minimum. As will be seen later in the discussion of qualitative results, some students were able to make comparisons between the simulations and what they had seen either in hospice or hospital placements. For the vast majority the simulations exposed the students to an area of palliative medicine they had not encountered elsewhere in their training, as the fact remains that most students will not experience meeting or caring for someone who is dying during their undergraduate years.<sup>(164)</sup>

Study participants represented approximately one-third of the 4<sup>th</sup> year cohort. As pre-simulation confidence was found to be low, it is possible that confidence amongst the remaining (non-participant) students in the year 4 cohort may also be low in this area of patient care. This is a concern as it is anticipated that most (if not all) of this cohort will qualify as Foundation Year 1 doctors within 10-12 months of the simulation study, and will be caring for dying patients with a low level of confidence to do so.

Results of study 3 demonstrated a clear increase in confidence as the result of participation in a simulated scenario, observation of peers, and provision of feedback. This is not surprising in itself as there have been many studies looking at the positive correlation between learner self-reported confidence following simulation-based education.<sup>(165)</sup>

Whilst students were informed of the clinical background to the simulated patient, all five scenarios differed from one another. This meant that each student had to engage with their scenario in a different way to the interaction they observed when their peers were undertaking their scenarios, in short, they simply couldn't copy their colleagues. The primary researcher designed the simulated scenarios in this way to foster a level of uncertainty similar to that which foundation doctors

report experiencing on the wards. This is important as the same level of uncertainty and associated anxiety cannot be achieved from a lecture or case-based discussion. Whilst little is documented with respect to the use of simulation in the care of the acutely dying patient, there is much evidence supporting the use of simulation in the acutely unwell patient and arguably parallels exist between the two clinical situations. Newly qualified doctors have been shown to develop anxiety when they suddenly find themselves responsible for the care of a deteriorating patient. Over 20 years ago it was recognised that a significant contributory factor to this anxiety is the element of exclusion of students from such patient encounters at undergraduate level, the consequence being a high risk of medical error occurring when those same individuals are faced with the responsibility of care provision in the post-graduate setting.<sup>(53)</sup> Two decades of research into the value of simulation have since provided a strong case for its integration into several areas of undergraduate curricula, with allied healthcare colleagues being quick to pick up on this teaching modality in the face of diminished opportunities within clinical placement.<sup>(59, 166)</sup> Those healthcare students who undertake simulated learning find that it is the challenge of the learning environment provided by educators that encourages them to think critically about how they will treat the patient in front of them, or how they will speak with the family member who is present.<sup>(59)</sup>

These challenging exposures, critical reflection, new learning and adaptations to personal practice are what link the constructivist approach to simulated learning, as introduced in chapter 3. In summary, the constructivist theory proposes that learners develop knowledge through their own activities rather than simply being taught didactically.<sup>(67)</sup> That is not to say that prior knowledge is unimportant, but rather that previously learnt knowledge applied in a new learning environment will facilitate the construction of new learning that is individualised and adaptive.<sup>(165, 167)</sup> Simulation provides a realistic context in which learners can explore and experiment with the opportunity to observe real-time results of their actions.<sup>(167)</sup> This was fundamental to the success of the simulations in this study. Students were able to recap prior learning during the pre-simulation revision sessions. This knowledge would not have been new for the students as they would have learnt its contents through the medical course to date. However, students did not know the simulator may die, and they did not know what the response of the relative

was going to be. This created uncertainty within the simulated task, making it necessary for students to adapt to the clinical situation as it progressed. Observing students were able to identify practices that differed from their own, and make a decision whether this would be something they would consider adopting as part of their own practice.

Not only did the results of study 3 demonstrate a post-simulation increase in confidence, it demonstrated that this increase was sustained over a six-month time period. It could be argued that student confidence will improve over time without specific educational intervention, however results of this study demonstrate that significant improvements in confidence can be achieved almost immediately through the exposure of students to a simulated educational experience, and that this confidence is sustainable. With the exception of one sub-section of the SEPC scale, there has been no evidence in this study that the improvement in student confidence seen has solely been attributed to the passing of time between measurements. It is also entirely feasible that confidence scores could worsen over time, however this study has not seen any evidence in support of this.

Whilst findings of the systematic review reported in chapter 2 established that there is a growing body of evidence demonstrating improvements in confidence as a result of learning interventions in care of the dying patients, the only study that included a simulated intervention involving medical students was the feasibility study published by the primary author which used a different tool to the SEPC scale questionnaire. <sup>(80)</sup> Although this makes it impossible to draw direct comparisons, other studies have looked at changes in student confidence over time as a result of a simulated teaching intervention either within other areas of medicine and surgery, or with other healthcare professionals. In contrast to the sustained confidence demonstrated in study 3, these other studies have found that despite initial sharp rises in confidence following a simulated intervention, levels were not sustained over time leading the studies to conclude that further improvements in the post-simulation setting are limited. <sup>(166, 168)</sup> It was suggested that this failure to sustain confidence could be due to a lack of transferability of skills from the (artificial) simulated environment to the (real-world) clinical environment, and that a key factor limiting this transferability is the failure of integration of the subject matter across core practice areas within the curriculum.



This adds strength to the argument that as educators we need to address how we can improve the integration of care of the dying teaching into undergraduate curricula. Systematic review findings also highlighted that it is often a failure to integrate care of the dying teaching early enough at undergraduate level, instead leaving it to dedicated modules later on in training. Earlier integration within broader areas of medicine and surgery may be a start to addressing this, so that students can begin to appreciate early on that death and dying will affect every area of clinical practice irrespective of specialty.

Bandura's theory of self-efficacy may provide further support in this argument for earlier and broader integration of palliative care into the curriculum. As described in chapter 1, self-efficacy is an individualised judgement of one's ability to successfully perform a behaviour required to produce a specific outcome, <sup>(77)</sup> and is often dependent on the context in which it is being measured. <sup>(72)</sup> Perhaps it is this characteristic of context dependency associated with self-efficacy which contributes to the anxiety experienced by Foundation doctors. Whilst death and dying can be taught as a subject in its own right, it may occur across many specialties and present with a differing variety of symptoms. This is important to acknowledge because it means that no two patients will necessarily die in the same way, for example the patient dying from cardiac failure is likely to present with different symptoms to a patient dying from motor neurone disease, or bowel cancer, and do so over a different time-course. Integrating care of the dying into specialty teaching will help students develop their self-efficacy across a broader context of medical conditions, and integrating it earlier will give them the time to do this. The adaptability of simulations will then lend itself to providing students with a realistic environment in which to construct new learning around dying from multiple conditions, observing and assessing simulated patients with a variety of symptoms and palliative care needs (spiritual needs, emotional needs).

### 7.1.1 Unexpected findings within qualitative data

#### 7.1.1.1 The effect of time on confidence

Whilst this study has demonstrated that confidence has been sustained, it was important to determine whether the passing of time itself had any impact on six-month confidence scores. Further improvement in confidence as a result of time

was not anticipated. Analysis of SEPC data using one-way analysis of variance (ANOVA) for repeated measures and pairwise analysis demonstrated that whilst SEPC scores for communication skills and patient management have not significantly changed over the six-month time period, there has been a significant increase in confidence with respect to MDT working as a result of time.

This finding may be the result of students having spent more time with multidisciplinary teams over the six-month period between data collection, which may have led them to develop further confidence in this area. However, they will also have seen and spoken with more patients and time has not affected these areas in the same way. This suggests there may be an alternative reason for the observation.

A more plausible explanation might be found by looking at the mean scores themselves. Whilst the pre-simulation MDT working score sits between the mean scores for the other two domains, in the immediately post-simulation setting students have, on average, marked a MDT working score that is 7.3 and 8.8mm lower than that of patient management and communication skills respectively. By the time six-months had elapsed mean scores for all three domains were much more in alignment, calculated to be within 2.8mm of each other.

#### 7.1.1.2 Lower scores for MDT working

The reason why MDT scoring was lower than the other domains in the immediately post-simulation setting may be the result of the nature of the simulated scenarios in the study. Whilst patient management and communication skills were heavily featured in the scenarios, there were no other members of the MDT present with whom the students had to interact. The decision not to have any MDT members was made following the outcome of the feasibility study in which a trained nurse was present for all scenarios. When developing the simulations for this study, it became apparent that the budget would not allow for a trained nurse to be present for all scenarios. As a result, the decision was made not to have any MDT members at all.

This might explain why the simulations had less of an impact on the MDT working scores within the SEPC. In other intervention studies, changes in pre-

test/post-test MDT scores were comparable to those observed in the other two domains, and in those studies there is evidence of MDT exposure.<sup>(99, 103)</sup>

## **7.2 Discussion of qualitative data findings**

### **7.2.1 Desire for preparedness**

There was almost unanimous desire from the students to be as well prepared as possible for their futures as junior doctors (Theme 5), and one of the aspects of patient care that arose in both the focus group discussion and feedback sessions was the element of patient centeredness (Theme 4). Overall students appeared unclear about how they should communicate with the dying patient, with reasons appearing to be two-fold. Firstly, students were aware that the patient was a simulation mannequin and not a real patient. For them this detracted from the reality of the scenarios, with students stating that as the patient was a 'dummy' they didn't know how much to communicate with them. However, the second, bigger issue influencing communication was the fact that the patient in the scenarios was unconscious and did not provide the student with any verbal or non-verbal feedback. Students acknowledged the challenges of communicating with the dying, with some students responding to this complexity by simply not communicating to the simulated patient at all, perceiving that the patient could not be included in the consultation any further once they had introduced themselves.

As a result, students felt the simulations were not particularly patient focussed, but rather more focussed on the relative in the room. This finding adds to concerns about student preparedness to care for the dying, with a potential failure to realise that even the unconscious dying patient may be able to hear and feel what is going on around them, respond to external stimuli such as pain and discomfort in a non-verbal way, and as such should be included in the consultation every bit as much as a conscious patient would be. Studies of previously unconscious and sedated patients who have since recovered from their period of illness demonstrate the importance of maintaining communication even if it is thought the patient cannot hear you, with individuals reporting being able to hear, emotionally respond to, and feel comforted by direct verbal communication from when being cared for by healthcare staff.<sup>(169, 170)</sup> Further

studies have conceptualised the challenges with respect to communicating with the unconscious, which include a limited knowledge of healthcare staff about why or how to communicate with such patients, and a limited knowledge of the needs of an unconscious patient.<sup>(171)</sup>

It is important that educators provide students with the opportunity to practice communication with the unconscious and dying so that they can learn how this is done and appreciate the value of doing so for both the patient and attending relatives. The constructivist approach to learning would lend itself to addressing this deficit in knowledge. Any pre-conceived ideas students have regarding communication with the unconscious dying patient will be challenged by their new experience in the simulated environment. The student may initially feel uneasy when talking to such a patient, but recognising this unease itself is important as educators can use this to encourage the student to identify why they felt uneasy, and construct a new understanding from this experience. By reflecting on what they could change within their practice to make future situations less uneasy will enable them to build upon and modify the learning they have achieved.

That being said, the decision to include an unconscious patient in all five scenarios has highlighted a potential limitation of this study, and will be discussed later in this chapter.

### 7.2.2 Opportunity to learn complex skills

Learning complex skills was a major theme in itself, and was linked closely to Theme 5 (Preparation for the future) and Theme 6 (Curriculum change). Whilst detailed scripts were provided, the scenarios allowed the actors an element of artistic licence. The primary researcher felt this was important as it would not be possible to know how the students would manage their scenarios, and things that were said and done by the students were open to questioning by the actor if they felt it was necessary to do so. It was hoped that adopting this approach in all scenarios would allow flexibility, enhance realism and add to complexity to the simulations. This is important as all doctors need to be able to justify their clinical decisions in real life, and will be questioned by colleagues, patients and relatives as to what they are doing and why. The element of flexibility and unpredictability in the simulations created additional challenges for students, in particular the fact

that their role was not to cure the underlying medical condition but rather to manage the symptoms of that condition that were negatively impacting the patient. The complexity of the dying process was seen as new learning for many of the students who began to realise that patients will die in different ways. Students embraced this complexity, and found that the simulated environment allowed them the chance to explore management options and learn from any errors they may have made. These were encouraging findings, and adds to findings in studies which have shown that higher perceived self-efficacy is demonstrated in those students who embrace challenging situations as it gives them enhanced opportunities to develop new skills.<sup>(61)</sup>

In all scenarios the participating students were made aware that simulated patient had been recognised as dying by the (fictitious) consultant in charge of the patient's care. This had been documented in the mock patient record and all students were encouraged to read this soon after entering the simulation room. The students did not know that in some of the scenarios the patient was going to die mid-scenario. It is this aspect of the scenarios which makes this study stand out from many others that have been published with respect to the unexpected death of a manikin during simulation. Those that have been published focus on the outcome of unsuccessful cardiopulmonary resuscitation,<sup>(61)</sup> or relate to nursing students,<sup>(59, 60)</sup> and in all cases there is a positive recommendation for the adoption of simulation in teaching.

The primary researcher wanted focus of the simulations to be on how to manage an actively dying patient, and not about how to recognise a dying patient. This latter skill is complex and often senior colleagues find this a challenging area of medicine, especially if they have been treating their patient for a number of years with a chronic condition. Instead, the intention of the scenarios was to give students the opportunity to develop skills in how to manage the symptoms of an actively dying patient, and to develop key communication skills with relatives of such patients. Equally it was important that students did not feel they should be heading down the route of trying to get the patient better by instigating further investigations and carrying out any examinations that would not benefit the patient.

The question of whether a simulated patient should be allowed to die has generated debate within the literature. A review published in 2013 looked at the

controversies surrounding simulated patient death. <sup>(58)</sup> Concerns are raised about the potential for negative psychological effects of simulator death on learners in simulations where death is not an expected outcome of the scenario. Despite such concerns, students participating in such scenarios do not appear to report any concerns themselves, do not feel it would prevent them participating in future simulations and do not feel it distracts from the objectives of the learning experience. The review concludes that there is currently no evidence to support the concerns raised and that educational benefits of simulated death far outweigh the risks. The review provides some general recommendations as to how educators should conduct simulated death scenarios. These include ensuring facilitators are comfortable in dealing with patient death and are trained to manage student learners in this environment, ensuring there is a pre-briefing stage to the simulations, ensuring participants are made aware that simulator death is a possibility, provide a debriefing session and provide support for any students who become distressed. The simulations in study 3 adhered to all these recommendations, and at no point did any student become distressed or ask to leave the simulations. This is an important outcome of the study simulations as it will add further support and reassurance for those who may have concerns about incorporating this type of palliative care teaching into the undergraduate curriculum at Brighton and Sussex Medical School.

### 7.2.3 Simulated learning environment

Notwithstanding the general view that a simulated environment can never fully represent real life experiences, students believed what they felt during their individual scenarios was the closest they could get to a real life situation. This was captured in Theme 2 (Simulated learning environment), and was strongly linked with Themes 3 (Learning complex skills) and Theme 6 (Patient centeredness). For some students the simulations were comparable to those clinical encounters witnessed on the wards and provided them with an opportunity to be actively involved, for others it was the first time they had seen or experienced anything related to a dying patient. Realism, or fidelity, is a fundamental factor when considering the structure and content of simulations. It is important to foster enough reality to enable the students to appreciate how learning can compare to clinical practice, but not create an environment that is

so realistic that it jeopardises the student's concentration at the task in hand. <sup>(172)</sup>  
<sup>(173)</sup> It was important for the primary researcher not to lose sight of the main aims of the study which centred around confidence and preparedness. Care of the dying patient and their relatives is a complex skill and it would have been very easy to inadvertently create a simulated environment that distracted the students, with additional noises and interruptions as would be experienced on the wards to add to the fidelity of the scenario. However, creating such a complex environment may have risked damaging student confidence rather than improving it.

Studies suggest an alternative viewpoint to the strength of simulation in medical education, seeing it as a way of providing a framework for focussed and repetitive teaching, with students refining their skills until their performance becomes reproducible and consistently accurate.<sup>(172)</sup> Whilst simulation is ideal for learning skills by repetition, it can be argued that it is also an teaching modality that lends itself to adaptation in the face of a shifting clinical environment. By its very nature, dying can be an unpredictable clinical situation alongside the reaction of relatives present at the bedside. The purpose of the study simulations was not to provide the students with a 'one size fits all' approach with stock communication phrases they can churn out at awkward moments, but rather to enable them to experience how they react in such challenging situations, think about what they have learnt within their scenarios and from the scenarios they observed and look to identify positive practices from the experience upon which they can continue to build their learning.

From a constructivist perspective the simulations needed to maintain enough alignment with real life situations to enable the students to explore their learning and construct new meaning from the situation, but without causing fear and panic within the students. The three aspects of constructive alignment (curriculum objectives, teaching activities and assessment) can be applied here to simulated learning, where curriculum objectives relate to the knowledge medical schools expect students to possess in order to achieve graduation, teaching activities relate to how educators impart this knowledge in order to develop student learning, and assessment relates to either the examinations held by the medical school (or educational bodies) or, more practically, what Foundation doctors are going to be expected to do on the job.

As explained in chapter 1, assessment of palliative medicine topics does not always feature in medical school examinations thus making it difficult to assess this alignment. So instead, by looking at Foundation doctor feedback we have already seen that poor alignment is likely to be responsible for the significant distress amongst Foundation doctors when caring for the dying. Simulations could provide a practical way of realigning curriculum objectives to match the realities of caring for a dying patient on the wards.

#### 7.2.4 Evaluation of the curriculum

Linking the status quo of the current undergraduate curriculum with desire for change were Theme 5 (preparation for the future) and Theme 6 (curriculum change).

Students were able to identify positive aspects of the current curriculum, and in particular many students who had completed their hospice placements highlighted their value in terms of teaching general palliative medicine. Whilst some acknowledged they did not see an actively dying patient during hospice placement, they felt they learned a lot around death and dying as well as the practicalities of prescribing and drug dose calculation. Students discussed the opportunities they had to converse with patients who were aware they were going to die as a result of their disease, which often led to open dialogue around what would be a difficult subject were it to be held in a different setting.

A small number of students found hospital placements accommodating when it came to speaking with deteriorating patients, particularly elderly medicine and general practice placements. However, the general feeling tended to be that general hospital placements were not the setting where they learnt much palliative medicine.

Students suggested that earlier integration of palliative medicine and care of the dying teaching would be welcomed, with a feeling that they suddenly get it thrust upon them when they reach their 4<sup>th</sup> year of training. However, there was a lack of consensus as to the format they felt this teaching should follow if introduced at an earlier point in the curriculum. It is difficult to ascertain what would work best for the general medical student population in terms of teaching on caring for the dying given the inconsistencies between undergraduate curricula.<sup>(164)</sup> In chapter



1 the role of the Association for Palliative Medicine (APM) Specialist Interest Forum for Undergraduate Palliative Care Education was outlined with respect to mapping of undergraduate curricula to GMC recommendations.<sup>(14)</sup> This work is still ongoing, and it can be seen how it follows the underpinning principle of constructive alignment discussed earlier in this chapter.

Students were clear that whilst they saw value in the simulations, they shouldn't be seen as a substitute for hospice placements. This collective student view is shared within the literature that simulation will never be a substitute for bedside teaching or a replacement for good educators.<sup>(174)</sup> Whilst this study has never suggested this to be the case, bedside exposure of undergraduates to dying patients has clearly documented limitations. Some of these limitations are generic to all patient encounters and include increasing unavailability of senior staff to provide teaching at the bedside due to clinical pressures, and challenges following up patients due to increased patient turnover within hospitals.<sup>(175, 176)</sup>

The unstructured and opportunistic nature of bedside teaching are also cited as major disadvantages, both of which are enhanced by the (appropriate) position of the patient as the main focus of all encounters. This has to be the case as patient safety and care will always be a primary concern over and above student teaching in the clinical setting. Added to that will be time pressures on bedside teachers, who are often only able to provide teaching when their work schedule allows given the increased pressures to see patients and complete paperwork. Factors associated specifically to dying patients include the uncertainty and unpredictability of their condition,<sup>(177)</sup> as well as the fact that relatives may wish to spend long periods of time at the bedside of a dying loved one and may not want this precious time disturbed for teaching purposes.<sup>(177)</sup>

Simulation has the major advantage over bedside teaching in that it places the student at the centre of learning, with many studies indicating that simulation using patient actors is a good way of learning bedside skills.<sup>(178)</sup> In the context of such bedside limitations, the results of this study provide evidence to recommend simulation as an adjunctive and enhancing teaching method in undergraduate medical education rather than a substitute. It is never going to be possible to teach students how to manage every aspect and nuance in the care of a dying patient, but rather to provide them with the fundamental principles of management so that when they enter the room of a dying patient for the first time

as a newly qualified doctor, they have experience they can draw upon to guide their management if they find themselves in a situation where there is less than adequate support. The opportunity to enhance prior didactic learning by applying it to a safe clinical setting further strengthens the argument for the use of simulation as an adjunct.

#### 7.2.5 Factors influencing medical student attitudes and learning in palliative care

As part of this discussion it is important to recognise those factors which are likely to influence the attitudes of medical students towards palliative care at an individual level, as well as the influence on the learning achieved. Whilst we did not specifically measure student demographics or personal characteristics as part of the simulation study, it is possible these have exerted an influence and in particular may have influenced the decision for many students not to participate in the study as discussed in chapter 5.7. Throughout the simulated study communication with both the patient and relative was essential and was a feature within each scenario. There is some evidence within the literature which suggests that gender identity can influence attitudes towards patient communication.<sup>(179)</sup> One study of 118 American medical students found that whilst female medical students displayed a more positive attitude towards communication skills, it was the male medical students who recorded a higher level confidence in their ability to communicate in comparison to their female student colleagues.<sup>(180)</sup>

The outcomes of a much more recent study (2020) of general university students (including healthcare trainees) have suggested that older students and those who identified as female and white were less likely to have negative attitudes towards palliative care. Equally less likely to have negative attitudes were those who has experienced family members being hospitalised and or receiving palliative care. In contrast those students who did not see the value in end of life care or who had little knowledge of palliative care were more likely to have negative attitudes.<sup>(181)</sup> It is important that we recognise that such characteristics are likely to have influenced the results seen in our study, and once again future study could look to gather such data on student demographics and compare to results in published literature.

## 7.2.6 Unexpected findings from qualitative data

### 7.2.6.1 Perceived lack of patient centeredness

As evidenced in focus group data in chapter 5, many students felt the scenarios were far more centred around the relative than the patient. This was an interesting finding and ties in with the observation that many students appeared unclear about how to communicate with the dying patient, or in fact whether they should be communicating with them at all. In a few cases students spoke to the patient whilst examining them, and directly referred back to the patient several times through the scenario. The majority, however, appeared to stop speaking to the patient after their initial introduction. It became clear during analysis of focus group transcripts that the main reason for this lack of communication was due to the misconception held within the groups that the patient probably couldn't hear them. This finding is interesting as it was the communication skills questions within the SEPC questionnaire that scored the lowest in the pre-simulation setting (Table 5.3), but which demonstrated the greatest improvement in the post-simulation setting (Table 5.3).

This is just one example of a key area where simulating the care of the dying patient along with the associated feedback and reflection could be used to help reverse misconceptions and allow students to develop the skill of how to communicate with the dying, and why this is important.

### 7.2.6.2 Level of disagreement as to where the simulations would best fit within the curriculum.

This was the subject of much debate within the focus groups, with several students unable to agree on where the simulations would best fit within the curriculum. Students were unanimous in their agreement that the simulations would be a valued addition, and many provided a well thought through rationale as to where they felt they would best fit. Some felt the simulations would be better placed towards the end of the medical school curriculum, at a time when they would benefit the most from the teaching given the fact that they would soon be working as FY1 doctors. Others felt the 4<sup>th</sup> year would be best as that is where the bulk of their oncology and palliative care teaching occurred. It was unexpected that students would suggest the simulations were placed any earlier

than this, however several students suggested that the second year would provide them with early exposure to death and dying, and as such would afford them the opportunity to build upon this learning during the remainder of their time at medical school. The main argument against earlier simulations was the fact that students would be unlikely to have developed enough knowledge around complex communication and symptom control for the simulations to be as effective as they could be. This desire for early simulation integration may be the result of the overall desire of medical students to receive more palliative and end of life care education earlier in their medical school curricula, as evidenced within the result of the systematic review (chapter 2)

### **7.3 Conclusion**

This chapter has provided an in-depth discussion of the findings of empirical study 3. Quantitative results have been discussed with particular reference to the three time points of data collection, the sustained increase in student confidence and what this means for simulation as a way of teaching medical students how to care for the dying. Unexpected findings in the quantitative data have been explored with possible explanations offered as to why these findings may have been seen.

The second section of this discussion chapter explores the qualitative aspect of the data, specifically in relation to the themes that were developed from thematic analysis of focus group data. By drawing together the overarching messages from the themes, it has been possible to evidence the value of the simulations from the student's perspective as well as provide insight into how the participating students handled the simulations and coped with the emotive nature of the subject matter.

In the final chapter of this thesis, final conclusions will be drawn, strengths and limitations discussed, and implications for medical education will be outlined in both local and wider contexts. The chapter will summarise by offering suggestions for future research and development.

## **Chapter 8: Conclusion**

### **8.1 Summary of key findings**

This thesis provides a detailed report of the work undertaken in partial fulfilment of the requirements of the University of Brighton and the University of Sussex for the degree of Doctor of Medicine. The overarching aim of this work was to determine whether simulation could improve the confidence and preparedness of medical students to care for a dying patient and their family.

Chapter 1 provides context to support the chosen subject matter detailed in this thesis, and outlines published literature which highlights the issue of ongoing anxiety and low confidence amongst Foundation doctors in their provision of care to dying patients and their families. Reports outline the continued concerns that failure to address these issues has the potential to cause long-lasting psychological distress to our doctors and ultimately risk compromising patient care. Whilst literature report on these issues being present amongst qualified doctors, little is known about the confidence and attitudes of medical undergraduates to provide care to the dying.

The systematic review reported in chapter 2 was therefore conducted in order to begin addressing this gap in knowledge and looked to identify three key areas: To find out what is known about medical student confidence to care for the dying, identify which tools are being used to measure this confidence, and report how successful educational interventions (where used) have been in positively changing confidence amongst the medical undergraduate population.

What was found was that baseline confidence in medical students from a variety of countries is reported to be low, with many students calling for earlier and increased representation of palliative and end of life care teaching within their medical school curriculum. Interventional studies within the review demonstrated that specific and focussed palliative care teaching led to increased student confidence in this area, however the types of intervention varied as did the tools used to measure confidence. Despite this the SEPC tool was found to be the only one documented to have been validated for use in medical students and as such provided a rationale for its used within the simulation study (empirical study 3) reported in this thesis. The results of the review have been published.

In addition to the above, chapter 1 also introduces simulation as a teaching method widely adopted within medical education and highlights its potential for greater use within palliative and end of life care teaching, providing an argument for the conduction of further research to ascertain its value in the specific teaching of care of the dying patient. The associations between simulated learning and the constructivist theory of learning have been explored, and the importance of aligning an educational curriculum to intended learning outcomes has provided further foundation to support the need for the research detailed in this thesis.

Empirical study 2 (chapter 4) reports on a cross-sectional study conducted amongst BSMS medical students to ascertain their attitudes towards caring for a dying patient and their family, and determine whether age, gender identity, year of study or degree status had any influence on these attitudes. The study was conducted using a tool validated for use in medical undergraduates (Thanatophobia Scale questionnaire) and was a tool familiar to the primary researcher having conducted and published an earlier feasibility study. What was found was that second-year students possessed a greater degree of anxiety to care for the dying in comparison to any other year group. This finding was statistically significant and the reasons why this may be the case have been explored with the chapter. It was also interesting to find that whilst gender identity and degree status had no statistically significant effect, it was seen that thanatophobia score decreased (corresponding to a reduction in anxiety) as student age increased, and this was a statistically significant finding.

Chapter 5 reports on the main study within this thesis and sought to answer the main question of whether simulation can improve the confidence and preparedness of medical students to care for a dying patient and their family. Detailed methodology of how the study was conducted is reported in chapter 3. In total 38 students participated in the study, each participating in a single simulated hi-fidelity scenario involving a dying patient (manikin) alongside an actor playing a visiting relative. Students attended the simulations in groups of 5, and each group participated in a focus group once all simulations were completed.

Results of the quantitative element of study 3 demonstrate that the simulated experience undertaken by participating students has significantly increased their level of confidence to provide care to dying patients and their families with particular reference to communication skills, patient management and multidisciplinary working. Results have also demonstrated that student confidence is maintained over a six-month time period for all three domains, and that this finding is statistically significant.

For the qualitative data, six main themes were identified following thematic analysis of focus group transcripts. Results demonstrate that students feel the undergraduate curriculum could do more in preparing them to provide care to dying patients and their families. They reported feeling a greater sense of

preparedness as a result of participating in the simulations and particularly coveted the ability to observe and receive feedback from peers. Students would consider adoption of the simulations into the undergraduate curriculum as a positive step to improving preparedness of medical students at BSMS, but did not necessarily feel they should be a substitute for hospice placements. Students highlighted areas where improvements to the simulations could be made, particularly in relation to realism and patient centeredness.

## **8.2 Clinical implications for medical education**

Stress and anxiety experienced by FY1 doctors when caring for the dying is generally reported to be the result of a lack of confidence and preparedness from prior training. Current undergraduate teaching is not providing students with the level of preparedness required to care for the dying, and medical education institutions need to evaluate their curriculum to see where positive changes could be made to align teaching in end of life care and care of the dying with expectations (outcomes) placed on FY1 doctors.

The results of this study have shown that simulating the care of the dying works in improving confidence in medical students to provide care to a dying patient and their family, with increased confidence being maintained over at least 6-months. Furthermore, students feel better prepared to care for the dying following their involvement in the study simulations. In the same way that simulation features in other areas of undergraduate teaching, it could equally be adopted within palliative care curricula as a way of increasing exposure of medical students to care of the dying in a safe and supportive environment. The flexibility and adaptability of simulation scenarios lends itself to cater for different learning needs of students, and can be focussed on addressing the learning outcomes set out by both the GMC and the APM. Mapping of the APM curriculum to recommended GMC outcomes is likely to better clarify the expectations of qualifying doctors, but also of medical schools. Complex areas of patient care such as specific symptom control management, addressing spiritual and religious needs and discussing clinically assisted hydration and nutrition needs can be the foundation subjects on which to base scenarios. Provision of feedback will enhance student learning by allowing students to reflect on how they performed during a scenario, and think about how they might change their practice when



they are faced with a similar scenario in the future. Peer observation will also allow students to observe a way of practising that may differ from their own, adopting new ways of thinking and approaching the subject matter. This is the essence of the constructivist theory of learning.

### **8.3 Implications for BSMS**

Despite there being a statistically significant increase in thanatophobia amongst 2<sup>nd</sup> year students, the overall trend by the end of the 5<sup>th</sup> year was a fall in thanatophobia to a level below that seen in the 1<sup>st</sup> year group. However, significance testing has shown us that the level of thanatophobia experienced by students across their medical school training does not significantly change over time. Equally as time progresses our students experience less thanatophobia as they get older. It can be argued that a degree of thanatophobia is not necessarily disadvantageous, and efforts to try and reduce thanatophobia level may not provide any benefit for the student or patients. It is reasonable to have some anxiety when thinking about caring for someone who is dying, especially as there is always a degree of uncertainty involved in this area of patient care, particularly when answering questions such as 'how long have I got left to live?' What may be more helpful for students is for them to know that this anxiety is normal, and for them to be able to recognise if and when this anxiety becomes detrimental to their learning and know how to access university student support systems. It is equally important for educators to recognise that individual characteristics and experiences are likely to influence student attitudes towards palliative care, which itself may affect how individuals learn palliative medicine. Highlighting the positive and exploring any negative experiences at both an individual and group level may prove valuable in shaping and guiding future attitudes and learning around death and dying.

The results of the simulation study and of the medical doctorate as a whole are encouraging. At the time of writing this thesis, plans are being put in place to integrate these simulations into the undergraduate curriculum at BSMS, and will be run during the preparatory time frame that exists between completion of medical finals (and subsequent qualification) and commencement of Foundation Year 1 jobs.

#### **8.4 Recommendations and future research**

- Utilisation of the mapped APM curriculum will help medical schools to identify areas where curriculum changes need to be made
- Medical schools should identify those teaching practices that will best deliver the education required to develop the knowledge skills and attitudes within our junior doctors to enable them to deliver care to dying patients with confidence
- Medical schools should consider whether they could utilise simulation in the teaching of care of the dying, particularly for those schools where this aspect of the curriculum is mainly theory/classroom-based
- Where available, medical schools can use existing simulation suites and draw from the experience of actors who are already trained in teaching of complex communication skills and role play
- The support of faculty with a clinical background in providing care to the dying, including palliative medicine specialists, general practitioners and elderly care physicians, will help to enhance the teaching and learning process
- Introducing the concept of the dying patient earlier in the curriculum could have a positive impact on the changes in thanatophobia we have seen. At a local level we have discussed the fact that BSMS students currently receive no palliative care teaching in their first year, and it may be there is opportunity to begin introducing some fundamental concepts surrounding palliative care, care of the dying, and patient death as part of core lectures. Students at other medical schools with a similar curriculum structure to that at BSMS may also benefit from earlier introduction of these core concepts.
- Opportunities exist for further research to build upon the outcome of the studies reported in this thesis. One question which may be asked is whether increased confidence and preparedness translates to improved academic performance? One way to answer this would be to undertake a study with two groups of students, where one group receives simulated teaching and the other receives the standard teaching. Both could then undergo formal examination (written / OSCE) with subsequent comparison

of results between the two groups. The standard teaching group would then be given the opportunity to receive the simulated teaching.

- Further research could explore whether an increase in confidence and preparedness translates into better patient outcomes or higher satisfaction in the relatives. Such research would have to be carefully planned, with a clear rationale for the choice of patient outcomes (or aspects of relative satisfaction) being measured as the results of such a study would have the potential to add significantly to the argument for or against the value of simulation in this context.
- Although simulation has been shown to demonstrate increased confidence and preparedness in medical students over a six-month time period, the other question that naturally arises is whether increased confidence and preparedness is maintained during FY1 training. To answer this there is opportunity to undertake a follow-up study with the same participants during their FY1 year, using the SEPC to measure their confidence one further time and compare it to pre-qualification scores.

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## Medical student confidence in care of the dying and their family: a systematic review

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### ABSTRACT

**Background** The General Medical Council expects medical graduates to care for dying patients with skill, clinical judgement and compassion. UK surveys continually demonstrate low confidence and increasing distress amongst junior doctors when providing care to the dying.

**Aim** This systematic review aims to determine what has been evidenced within worldwide literature regarding medical undergraduate confidence to care for dying patients.

**Design** A systematic electronic search was undertaken. Data extraction included measurements of baseline confidence, associated assessment tools and details of applied educational interventions. Pre/postintervention confidence comparisons were made. Factors influencing confidence levels were explored.

**Data sources** MEDLINE, CINAHL, EMBASE, ISI Web of Science, ERIC, PsycINFO, British Education Index and Cochrane Review databases were accessed, with no restrictions on publication year. Eligible studies included the terms 'medical student', 'confidence' and 'dying', alongside appropriate MeSH headings. Study quality was assessed using the Mixed Methods Appraisal Tool.

**Results** Fifteen eligible studies were included, demonstrating a diversity of assessment tools. Student confidence was low in provision of symptom management, family support, and psycho-spiritual support to dying patients. Eight interventional studies demonstrated increased postintervention confidence. Lack of undergraduate exposure to dying patients and lack of structure within undergraduate palliative care curricula were cited as factors responsible for low confidence.

**Conclusion** This review clarifies the objective documentation of medical undergraduate confidence to care for the dying. Identifying where teaching fails to prepare graduates for realities in clinical practice will help inform future undergraduate palliative care curriculum planning.

**PROSPERO registration number** CRD42019119057.

### Key statements

#### What is already known about the topic?

- Among all qualified doctors, foundation year 1 trainees spend the most time with dying patients and their families.
- Annual UK surveys continue to report low confidence and increasing distress amongst junior doctors when caring for dying patients.
- The General Medical Council expect medical graduates to demonstrate skill and appropriate clinical judgement when caring for the dying.

#### What this paper adds?

- Low student confidence in caring for the dying has been documented within several countries over the past 26 years.
- Lack of clinical exposure to dying patients at undergraduate level, as well as poorly structured palliative care curricula are key factors contributing to observed low confidence.
- A demonstrable increase in confidence has been observed in those studies documenting the implementation of a teaching or experiential intervention.

#### Implications for practice, theory or policy

- Medical schools need to better prepare our graduates to care for dying patients and their families with confidence and without undue distress.
- Level of exposure to dying patients currently offered within medical undergraduate curricula requires review, with critical appraisal on whether this is being offered at a level appropriate to achieve the expectations bestowed on graduates by governing bodies.
- Alternative ways of exposing students to dying patients needs to be explored.

### INTRODUCTION

Across all training grades in the UK, foundation year 1 (FY1) doctors spend the most time with dying patients,<sup>1</sup> and

realistically may find themselves looking after dying patients on their very first day.<sup>2</sup> In 2018, the General Medical Council (GMC) published updated guidelines for newly qualified doctors in its key document 'outcomes for graduates'. This document makes it clear that newly qualified doctors must be able to make appropriate clinical judgements when caring for patients at the end of life.<sup>3</sup>

In 2013, a survey of junior doctors demonstrated a lack of confidence and preparedness in general palliative care skills among FY1's, and of those surveyed almost two-thirds reported becoming distressed when caring for the dying.<sup>4</sup> This may not be surprising given findings that many FY1's report having experienced little or no exposure to dying patients at undergraduate level.<sup>4</sup> Contemporary research continues to demonstrate a lack of confidence among trainees in caring for dying patients who have lost consciousness.<sup>5</sup>

In 2013, a systematic review reported on the tools used to assess the effectiveness of undergraduate palliative care education, and found that there were no universally accepted validated questionnaires to measure this construct. The review demonstrated that there was much in the literature pertaining to changes in healthcare students' attitudes, skills and knowledge as a result of educational interventions, however, it did not specifically seek to identify measurement of confidence in medical students in relation to the care of dying patients.<sup>6</sup>

Although some degree of overlap is acknowledged, the concepts of confidence and competence are recognised as separate entities within the literature. While increased experience and clinical exposure correlates highly with students' confidence to perform certain tasks,<sup>7</sup> this increased confidence does not necessarily result in increased competence as measured by formal assessment.<sup>8</sup> Nonetheless, a perceived lack of confidence can have a negative impact on an individual's performance.<sup>6</sup> What is clear is that the relationship between confidence and competence is complex,<sup>7</sup> and while the literature suggests one can be confident to perform a task but not competent to do so, the reverse can also be argued.

Another important distinction to make is that which exists between the concepts of confidence and attitude. Again, while a degree of overlap may be present, the two concepts are often treated separately. Examples of this can be seen within undergraduate<sup>9-11</sup> and postgraduate<sup>12,13</sup> literature. Furthermore, while confidence can be defined as the quality of being certain of one's abilities, attitude is defined as a feeling or opinion about something.<sup>14</sup>

In particular authors wished to look at whether students were confident at carrying out certain aspects of caring for a dying patient, from clinical assessment and prescribing skills, to communication with the patient and family.

**Table 1** Search terms

Main terms	Searched terms
Medical student	'Medic* adj3 undergrad*' 'Medic* adj3 student*'
Confidence	'confiden*' 'self-assur*' 'self-belief' 'self-esteem' 'attitude*' 'belief*'
Dying	'end of life' 'dying' 'death' 'palliat*' 'terminal*'

By clarifying and defining such seemingly subjective terms, a degree of objectivity can be fostered which in turn will help authors clarify what it is they wish to investigate when formulating a research question. The aims of this systematic review are to identify literature pertaining to medical student confidence with respect to caring for a dying patient and their family, to critically appraise how confidence has been measured, and explore the impact of medical education interventions on confidence levels.

## METHOD

### Protocol and registration

This systematic review is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines<sup>15</sup> (online supplementary appendix 1).

### Search strategy

In order to identify studies that reported measures of medical student confidence with respect to looking after dying patients and their families, a systematic electronic search using MEDLINE, CINAHL, EMBASE, ISI Web of Science, ERIC, PsycINFO, British Education Index and Cochrane Review databases was conducted on 15 October 2019. Search terms used included permutations of the three main terms of medical student, confidence and dying (table 1), alongside appropriate Medical Subject Headings (MeSH).

Permutations of the main terms were combined using the command 'OR'. The results for each main theme were then combined using the 'AND' command. This ensured that at least one permutation for each main theme was included in the title or abstract.

### Eligibility criteria

Studies were included providing they met the eligibility criteria (box 1). No restrictions were imposed in terms of publication year, country of origin or study design as there was no rationale to do so. Peer-reviewed articles were included alongside any other published works (abstracts, letters and editorials) provided they satisfied the eligibility criteria. Worldwide literature was

**Box 1 Eligibility criteria****Inclusion criteria****Published works that included:**

1. Medical students as study subjects.
2. Measurement of confidence (via any methodology).
3. Care of dying patients (and not just palliative or end of life care in general).

**Exclusion criteria**

- ▶ Were not written in English language.
- ▶ Referred to 'end of life' without specific reference to dying patients.
- ▶ Assessed attitudes without specific reference to confidence.
- ▶ Did not include adult patients.

included to facilitate a broader understanding of what is known about undergraduate confidence, allowing comparisons to be made with undergraduate curricula differing to that adopted in the UK.

**Study selection**

All studies identified through database searches were exported into Excel for deduplication. Remaining studies were tabulated and arranged alphabetically by author surname for more detailed review.

Due to the large number of studies identified, the primary reviewer (GW) excluded those that did not include all three inclusion criteria within the title and abstract alone. A second reviewer (RW) independently assessed 10% of these for eligibility (randomly selected studies).

Remaining eligible studies were retrieved using library services. Authors of unavailable studies were contacted to request an emailed copy, and were excluded if no reply was received. All successfully retrieved studies underwent independent full-text review (GW and RW). Any disagreements regarding study eligibility were resolved by a third independent reviewer (CL).

A finalised list of all eligible studies appropriate for data extraction and quality assessment was created. Reference and citation searching of these was conducted to identify further eligible studies not found through database searching.

**Data extraction**

Data extraction was undertaken independently by two reviewers (GW and EY). Data pertaining to study design, sample characteristics, significance of confidence levels and potential factors influencing confidence were extracted and tabulated onto an Excel data sheet. Data were checked for consistency and any discrepancies were resolved through discussion.

**Assessment of study quality**

The methodological quality of each study was assessed by two independent reviewers (GW and EY) using the

Mixed Methods Appraisal Tool (MMAT—V.2011).<sup>16</sup>

The MMAT tool was designed to address the challenges faced when critically appraising qualitative, quantitative and mixed-methods studies as part of a systematic review,<sup>17</sup> and as such was deemed an appropriate quality assessment tool to use for this systematic review given the methodological diversity found between the studies. Quality of studies can be scored as 0%, 25%, 50%, 75% or 100% depending on how many set criteria are met by the study being assessed. Example criteria include whether there is a clear description of participant randomisation, participant response rate and whether steps were taken to minimise bias within the study. Lower and higher percentage scores correspond to poorer and greater methodological rigour of each study, respectively.

To evaluate the extent to which both reviewers agreed on study quality (inter-rater variability), a Cohen's kappa ( $\kappa$ ) score will be calculated for each eligible study. A score of  $\kappa=1$  would imply perfect agreement between reviewers, while a score of  $\kappa=0$  would imply no agreement.<sup>18</sup>

**Outcome measures**

Given the heterogeneity of data gathering tools used within the identified studies, a mixed-methods approach to data synthesis and reporting was adopted for this review. Data were extracted regarding details of the tools used to measure confidence along with their frequency of use among the studies.

For those studies reporting quantitative data, baseline mean confidence scores were extracted. Where studies reported an intervention had taken place, changes in the pre and postintervention confidence means were extracted and discussed.

For studies reporting qualitative data, descriptive analysis was undertaken to identify factors influencing confidence among medical students.

**RESULTS**

Electronic database searches generated an initial 4301 studies. After deduplication ( $n=1582$ ), 2719 potentially relevant studies underwent title and abstract review. A total of 2626 studies were excluded at this point leaving 93 for full-text review. Reviewers (GW and RW) excluded 72 articles at this stage, but were not able to reach a consensus on 9 articles. These underwent additional independent review (CL) who agreed that three should be included with the remaining six excluded. In total, 78 articles were excluded leaving a final 15 articles eligible for inclusion into the review. Of note there were three articles where corresponding authors needed to be contacted in order to clarify queries regarding published data. While only one author replied, all three articles were excluded from the study, details of which are included in online supplementary appendix 1.<sup>15</sup>

**Study characteristics**

Study characteristics are detailed in table 3 (online supplementary appendix 2).

The majority of studies (n=4) were from the UK,<sup>19-22</sup> with the remainder published in Germany (n=3),<sup>23-25</sup> Australia, (n=2)<sup>26, 27</sup> USA (n=2),<sup>28, 29</sup> India (n=1),<sup>30</sup> The Netherlands (n=1)<sup>31</sup> and New Zealand (n=1),<sup>32</sup> with a collaborative study between the UK and USA (n=1).<sup>33</sup> Publication year ranged from 1993 to 2019.

Study quality ranged from 25% (n=4) to 100% (n=2) with an average score of 53% across all 15 studies. The majority of studies (n=12) lacked information regarding details of student selection and reasons for student non-participation, therefore, discussions about selection bias were not particularly rigorous.

A Cohen's kappa score ( $\kappa$ ) of 0.63 was achieved, which suggests there has been substantial agreement between both reviewers with respect to measurement of study quality.<sup>18</sup>

Of those studies using mixed methodology (n=4), the qualitative aspect was represented by way of thematic/content analysis of student feedback,<sup>20, 22, 27</sup> or response to open-ended questions.<sup>25</sup> No study was solely qualitative in nature.

Nine studies included an interventional component, with pre and postintervention measurements of confidence.<sup>19, 21, 22, 24-29</sup> One quasi-randomised controlled trial (RCT) was identified.<sup>28</sup>

**Participant characteristics**

Medical student sample size ranged from 6 to 449 participants. Eight studies included data pertaining to student characteristics, however, there was a lack of consistency between studies in terms of how characteristics were reported. With studies reporting gender identity characteristics (n=7), all reported a greater proportion of female participants (range 50%-74%).<sup>21, 22, 25, 28, 29, 31, 33</sup> Only five studies recorded participant age, with the most common age range being 20-30 years old.<sup>22, 25, 29, 31, 33</sup>

Eight studies included fifth/final year students.<sup>19, 20, 23, 24, 26, 30, 31, 33</sup> One study reported on students within years 3-6 inclusive,<sup>32</sup> with the remaining six studies including either second, third or fourth years.<sup>21, 22, 25, 27-29</sup>

Ethnicity was only reported in studies from the USA (n=3), with Caucasian students representing the majority of participants.<sup>28, 29, 33</sup>

**Measures of confidence**

A variety of tools were used to measure student confidence. The majority of studies (n=8) used Likert style questionnaires, adopting 1-4 scale,<sup>23, 24, 29, 31</sup> 1-5 scale<sup>28, 32, 33</sup> and 1-7 scale<sup>19</sup> variations. Visual Analogue Scales were adopted by four studies,<sup>20, 21, 26, 27</sup> (of which three included the Self-Efficacy in Palliative Care scale (SEPC)). Two studies employed a 1-10 numerical rating scale,<sup>25</sup> and a simple yes/no questionnaire

respectively.<sup>30</sup> The final study adopted a mixed-methods approach, and while the quantitative aspect measured student attitudes, it was the thematic analysis of focus group data that specifically looked at confidence.<sup>22</sup>

Across all studies data reported how confident students felt across a variety of domains within the care of a dying patient. These specific domains are discussed below, in descending order of prevalence.

**Confidence in managing the physical symptoms of a dying patient**

Ten studies reported some measure of confidence in managing the common symptoms experienced by dying patients, such as pain, nausea, constipation and anxiety.

Baseline scores within six studies demonstrated a general lack of confidence among medical students in the symptom management of the dying, with the majority of student scores falling into a 'not-confident' category, or with a mean result below 50% of the maximum achievable score. This was irrespective of which tool was used to gather the data, or whether it was an intervention study.<sup>19, 21, 23, 26-28</sup>

One medium sized study (n=125) measuring baseline confidence between third-year and fifth-year undergraduates with respect to 'patient management' (which included symptom control) found that while third years were generally quite anxious with this domain, fifth years demonstrated greater confidence in comparison (p=0.001, large effect size).<sup>20</sup> These results echo those of a larger study<sup>32</sup> (sample size=392) which compared confidence in symptom management of 3-6th year students. Using a Likert scale (0=low confidence, 5=high confidence), the study found that while confidence was low in year 3 (mean=0.6), it increased exponentially by year 6 (mean=2.9), without additional intervention and with a high degree of correlation.<sup>32</sup>

Interestingly the Dutch study<sup>31</sup> (n=213) found that the majority of students (60.5%) reported feeling confident in treating dying patients despite having an overall lack of confidence in providing palliative care in general. This shares some similarities with the UK/USA study which reported that UK students were more confident in managing pain in dying patients, including discussing the effects of medications, but less confident in discussing clinically assisted hydration (CAH) and nutrition (CAN) than their US counterparts.<sup>33</sup> This particular study gathered data using a 10-item Confidence in Treating Patients with Dementia in End-of-Life Care scale.<sup>34</sup> While the study found that students with previous experience were more likely to feel confident discussing CAH and CAN (p≤0.01), those lacking experience were more confident in prescribing pain medications (p≤0.05). Effect size was not recorded.

**Confidence in communicating and interacting with dying patients**

Six studies measured student confidence and comfort in communicating and interacting with dying patients, and results echo those for baseline confidence in managing physical symptoms. Five of the studies demonstrated a baseline confidence of less than 50% among students. One low quality study (MMAT score=25%) demonstrated that a small majority of students felt confident in answering a patient's questions about potential suffering or pain,<sup>26</sup> however, this appeared to be an outlying result as the same study also reported that students had low confidence when speaking with dying patients about prognosis and lack of beneficial treatment options. No supporting statistical analysis was undertaken.

Reporting within this domain were four interventional studies. Three of these studies demonstrated statistically significant improvements in confidence with communication when comparing pre and post-intervention scores ( $p < 0.001$ ). These interventions composed of palliative care lectures, problem-based learning and bedside tutorials,<sup>27</sup> a 90 min ward-based palliative care teaching module,<sup>25</sup> and an 8 and 13-day palliative care educational programme.<sup>21</sup> A fourth interventional study also reported an increase in student confidence after attachment to a 'preceptor' (specialist palliative care nurse), however no statistical methods were applied to these results.<sup>26</sup>

Two moderate quality (MMAT score=50%–75%) German studies (one interventional<sup>24</sup> measured student confidence in 'accompaniment' of a dying patient. Neither study defined accompaniment, however, it was implied that this construct pertained to spending time with the patient, and both studies found students to have a baseline confidence of 17%<sup>24</sup> and 20%<sup>25</sup> in this domain. The interventional study demonstrated that 55% of students felt confident in accompanying a dying patient after attending a dedicated teaching course ( $p < 0.0001$ ).<sup>24</sup>

**Supporting families of dying patients**

Five studies explored student confidence with supporting the families of dying patients.<sup>22 26 28 29 33</sup> One interventional study compared the effect of small group vs web-based interactive e-learning on student confidence, measured by a 24-item palliative and end-of-life self-efficacy scale.<sup>28</sup> Within the scale students were asked to rate their confidence with respect to conducting family conferences around end-of-life care discussions, dealing with angry family members and managing family conflicts during end-of-life care (scoring 1–4, not confident to very confident). While pretest scores were lower for the small group cohorts (mode=1, not confident) compared with e-learning cohorts (mode=2, a little confident), both groups scored higher (mode=3, moderately confident) on post-test scale application, although this was not statistically significant.

A second moderate quality (MMAT score=50%) interventional study found that 81% of students lacked confidence in teaching family members about end-of-life care at the bedside, and 74% lacked confidence to answer questions from family members about the dying process. After the implementation of a specific end-of-life curriculum, reported lack of confidence decreased to a statistically significant 12% and 21%, respectively. This was one of the larger sample-sized studies included within the review ( $n = 222$ ).<sup>29</sup>

A high-quality (MMAT score=100%) quasi-RCT ( $n = 109$ ) comparing small group learning with interactive web-based learning found statistically significant improvements in students' self-efficacy to manage certain aspects of family care, namely conducting family conferences and managing family conflicts with respect to dying patients. This improvement was found in both groups irrespective of teaching modality ( $p < 0.001$ ).<sup>28</sup>

**Addressing spiritual aspects of death and dying**

Three non-interventional studies documented student confidence in addressing the spiritual needs of the dying. One study highlights the potential importance of spirituality in the dying process of individual patients,<sup>23</sup> quoting that undergraduate training interventions have, thus far, failed to show evidence of improvement in student knowledge of such issues.<sup>23 35</sup> As a result the study justified focus on measuring student confidence in ability to address spiritual needs using a Likert-style questionnaire. Unsurprisingly 79% of students reported feeling non-confident in this area, and while no statistical analysis was performed, the study describes ability to address spirituality as being a major obstacle in undergraduate training.<sup>25</sup>

The second, joint UK-USA study used the Confidence in Treating Patients with Dementia in End-of-Life Care scale.<sup>34</sup> The study compared all participating medical students to a combined group of nursing students, summarising that medical students were less confident in discussing spiritual aspects of death and dying than the nursing students, though statistical significance of this was unclear.<sup>33</sup>

While the third study described data pertaining to several aspects of confidence in caring for a dying patient, it was the integration of spiritual aspects of care that students appeared to find most challenging, with 77% of respondents ( $n = 213$ ) rating themselves as not-confident.<sup>31</sup>

**Provision of psychological support**

Among other questions, one interventional study asked students to rate their confidence in providing hope and encouragement to patients and their families in relation to death, dying and terminal illness. Pre and postintervention confidence increased by 15%, with a borderline confidence level reported in the preintervention questionnaire (55% confident,



45% not confident). However, this was a low-quality study (MMAT score=25%) which lacked statistical analysis.<sup>26</sup>

The study comparing UK and USA medical and nursing students echoed the results seen regarding spirituality, with medical students being more likely to report low confidence in addressing psychosocial issues, although again no statistical analysis was offered. This study draws on literature which reports that confidence can be improved with increased exposure and observation of experienced colleagues in managing psychological aspects of a dying patient's care.<sup>33 36</sup>

One study specifically asked students to rate their confidence in integrating spiritual aspects when treating and guiding terminally ill and dying patients. It found this to be the lowest scoring domain, with just 23% of students (n=213) placing themselves in the 'confident' category.<sup>31</sup>

### DISCUSSION

This is the first study to highlight what is known about medical student confidence in relation to caring for a dying patient, identify how this has been measured, and describe the impact of teaching interventions employed by the studies in this review.

We found that among the studies in this review, 11 different tools were used to measure confidence. Given such heterogeneity, it is difficult to establish which were better at measuring the constructs of confidence or self-efficacy. However, some studies documented where their tools had been pilot tested for acceptability (n=4),<sup>23 25 28 32</sup> internal consistency<sup>31</sup> or validated as a psychometric test (n=4).<sup>20 21 27 29</sup> Of note three studies use the SEPC questionnaire,<sup>20 21 27</sup> which is the only tool validated for use in medical undergraduates. As such it could be argued that this affords the SEPC a more robust foundation for its adoption in the measurement of student confidence in this setting.

All studies in this review found that medical students report low confidence with respect to various aspects of caring for dying patients and their families. The majority of these studies have involved some form of intervention with pre-post measures of confidence, and although statistical significance of results has not always been reported, it can be seen that the interventions have led to an increase in self-assessed confidence among student participants.

The main factors influencing observed low levels of confidence have been related to insufficiencies within undergraduate palliative care curricula at the time of publishing,<sup>31 32</sup> lack of compulsory curricula pertaining to care of the dying or palliative care in general,<sup>23 26</sup> or failure to integrate care of the dying patient early enough into medical undergraduate training.<sup>24</sup>

There is a lack of clarity regarding the current organisation and funding of palliative care training within UK medical schools, with evidence of limited

leadership and course review—factors which may well be contributing to the failure of some schools to adequately educate medical undergraduates.<sup>37</sup> The ability of graduating medical students to care for dying patients is considered a core competency,<sup>3</sup> and surveys demonstrate that the majority of medical students regard learning how to care for a dying patient as being of high importance.<sup>38</sup> Despite this, junior doctor confidence in managing dying patients appears to be mainly developed from exposure in postgraduate environments,<sup>39</sup> strengthening the argument that teaching on the care of the dying patient could benefit from earlier integration into undergraduate curricula.

This does not appear to be unique to the UK. In 2000, a survey of US medical schools demonstrated that 100% of undergraduate courses incorporated education pertaining to death and dying,<sup>40</sup> with 27% of schools offering a separate 'death and dying' course by 2005.<sup>41</sup> Despite this, there remains no standardised undergraduate curricula to guide this teaching, which still takes the form of preclinical lectures.<sup>40</sup> Furthermore the number of hours dedicated to such teaching has remained unchanged since 2000.<sup>41</sup> The importance of experiential learning in providing students with opportunities to put their skills into practice is emphasised, particularly in the context of the 'millennial medical student', who is typically seen to be practical in nature.<sup>42</sup> Over the 23-year publication period, the majority of studies conclude that continued lack of undergraduate experiential learning remains one of the key factors associated with the persistent reporting of underconfidence of undergraduates to care for the dying.

With respect to spirituality, the GMC and WHO recognise the importance spirituality has in promoting health and managing disease.<sup>43</sup> The concept of spirituality does not have to be a religious one, as many without religious beliefs will describe having an important spiritual component to their lives.<sup>44</sup> It can be described as a deep-seated sense of belonging, meaning and purpose in life.<sup>45</sup> Despite the GMC requirement of UK medical schools to incorporate teaching on spirituality at an undergraduate level,<sup>3</sup> current teaching practices remain unclear with a lack of standardised approaches.<sup>43</sup> In contrast, the percentage of US medical schools offering teaching on spirituality rose from 13% in 1994 to 75% by 2006 due to the recognition of its importance on patient well-being.<sup>45</sup> Just two studies<sup>23 33</sup> (German and joint US/UK studies) in this review specifically comment on confidence in addressing the spirituality of dying patients. One concluded that increased exposure to and observation of professionals addressing spirituality will help improve undergraduate confidence.<sup>33</sup> The second study did not draw any firm conclusions.

### Limitations

Given the low number of studies meeting the inclusion criteria and heterogeneity of interventions, it is difficult to ascertain which interventions appear most successful in improving student confidence. This is made all the more challenging given that statistical analysis of results was only undertaken in approximately 50% of studies, with the remaining studies either reporting that analysis was not likely to be meaningful due to low sample size, or simply not mentioned at all.

Studies included within this review span seven predominantly western countries. The geographical location of these studies is likely to have been influenced by the fact that in order to be deemed eligible, studies had to be reported in English. It is not inconceivable that relevant and important studies from other countries may have been excluded in this process, and as such this will limit generalisability of review findings to non-western countries. Inclusion (and translation) of research from non-western countries may afford opportunities to identify cultural differences with respect to talking openly about death and dying, and how this informs undergraduate curricula on care of the dying patient.

All studies reported some measure of baseline confidence. However, it was found that in the majority of studies, measurement of medical student confidence in caring for a dying patient and their family only formed a part of the overall outcome measures for each study. As such measurements were made by asking of single (or very few) questions within a larger questionnaire, or from combining the results of questions grouped together. There was heterogeneity with regard to those aspects of patient and family care against which confidence was being measured, with the majority focusing on physical symptomology ( $n=11$ ) and communication skills ( $n=9$ ).

A further important consideration relates to the nomenclature adopted between the studies with respect to the main concepts being reviewed. The use of broad search terms was necessary to ensure studies were not inappropriately excluded, with particular reference to the concepts of confidence and dying. It is clear that certain terms are subject to multiple interpretations, with 'end of life', 'actively dying' and 'terminally ill' being used interchangeably but with inconsistent definitions.<sup>46</sup> The same is true for the concepts of confidence, self-efficacy and competence. Bandura<sup>47</sup> defines perceived self-efficacy as representing the confidence that one can use the skills necessary to cope with stress and meet situational demands. However, Bandura also states that perceived self-efficacy can be characterised as being competence based,<sup>47</sup> a definition that is shared by other published authors.<sup>48</sup>

Such challenges within definitions can be seen outside of the medical literature. For example, one study offers clearer definitions between the two concepts, but argues that observed increases in confidence may

arise from increased competence in the first place.<sup>49</sup> Further afield research highlights interweaved relationships between confidence and competence, recognising that as observers we feel uncomfortable if we perceive experts (be that a physician or car mechanic) to have low confidence—which may then cause us to question their competence.

A final limitation is in relation to the use of the MMAT. Reviewing authors (EY and GW) experienced some difficulties interpreting the tool guidelines when applying it to judge the eligible studies in this review. Both reviewers found some of the criteria overly complicated and difficult to follow, and on occasion poorly applicable to some of the more complex studies. This may in part explain why inter-rater reliability achieved a Cohen's kappa of  $\kappa=0.63$ , and while this suggests substantial agreement was reached, it also evidences a level of disagreement between both reviewers. Since the commencement of this systematic review it appears the content validity of the MMAT has been subject to in-depth review and subsequent revision based on findings that many other users have faced similar challenges in the application of this tool, with poorer level of agreement seen when applying it to qualitative and non-randomised studies.<sup>50</sup>

### What this review adds

This review has demonstrated a two-decade history of low confidence among medical undergraduates with respect to caring for a dying patient and their families, across a variety of countries. Measurements of confidence have been undertaken using a heterogeneity of validated and unvalidated tools.

In the past decade, increasing attention has been focused on the way medical students are taught to care for dying patients and their families, with governing body guidelines making clear the expectations of graduates in the care of one of the most vulnerable groups of patients. Despite this, junior doctors continue to report experiencing distress and a lack of confidence when caring for such patients in 21st century medicine.

As educators we must address the issues raised in the feedback we receive. It is clear that medical schools do not follow a standardised approach when it comes to teaching care of the dying, and where interventions are put in place it is unclear which ones achieve the best outcomes. This review has demonstrated that a lack of clinical exposure to dying patients and poorly structured palliative care curricula are repeatedly cited as being the main drivers perpetuating this ongoing feedback. It is hoped the results of this review will help support and guide critical appraisal of current teaching practices in learning to care for dying patients and their families.

In time this will facilitate the development of junior doctors with greater confidence to care for dying patients, paving the way for further study to demonstrate improved patient outcomes.

**Acknowledgements** The primary author would like to thank Ms Lisa McLaren, librarian at Brighton and Sussex Medical School for her expertise in systematic review methodology.

**Contributors** CW is the primary author of this work. He has contributed to all aspects of this review, carrying out the initial review, screening all articles for eligibility, full-text review of eligible articles, data extraction, quality assessment, assimilation of results and detailed analysis and discussion of these results. CW has developed this report and has undertaken all aspects of editing for publication. CW takes responsibility for the overall content as guarantor. EY assisted with detailed data extraction of all eligible articles. EY undertook detailed quality assessment as a second reviewer using the MMAT which facilitated the measurement of inter-rater reliability. EY has also been involved in the editing process, and has made recommended changes to the final manuscript. RW undertook initial screening of a random 10% of articles to ensure articles met eligibility criteria, and was involved in the full text review of all studies deemed eligible. RW has also reviewed the final manuscript for any necessary editorial changes. JW has assisted in the development of this manuscript by providing research expertise and support throughout its development. Regular reviews of the manuscript at supervision meetings to recommend edits. JW has reviewed the final manuscript and made changes prior to publication. CL has been the main reviewer for this review, providing her expertise in the field of mixed-methods research, and systematic reviews. CL acted as a third independent reviewer for those articles for which CW and RW could not find a consensus with respect to eligibility. CL has helped with the formation of Cohen's kappa score, and has made edits to the final document for publication.

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**Competing interests** None declared.

**Patient consent for publication** Not required.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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## Appendix B: PRISMA CHECKLIST for systematic review

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	40
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	40-41
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	40-41
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	40-41
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	41
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	43
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	42
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	42-43
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	44
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	44

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	43-44
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	44-45
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	45
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I <sup>2</sup> ) for each meta-analysis.	45-47

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	-
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	-
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	44
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	47-48
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	-
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	49-64
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	-
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	-
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	65-69
<b>DISCUSSION</b>			

Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	65-71
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	71
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	73-74
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	-

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

# Appendix C: PROSPERO study protocol for systematic review

**PROSPERO**  
International prospective register of systematic reviews



UNIVERSITY *of York*  
Centre for Reviews and Dissemination

## Systematic review

This record cannot be edited because it has been rejected

### 1. \* Review title.

Give the title of the review in English

Medical student confidence in care of the dying and their family: a systematic review

### 2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

### 3. \* Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

10/10/2018

### 4. \* Anticipated completion date.

Give the date by which the review is expected to be completed.

31/12/2019

### 5. \* Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

This field uses answers to initial screening questions. It cannot be edited until after registration.

The review has not yet started: No

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes

Provide any other relevant information about the stage of the review here.

Published



Published

**6. \* Named contact.**

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Geoffrey Wells

**Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:**

Geoff

**7. \* Named contact email.**

Give the electronic email address of the named contact.

G.Wells@bsms.ac.uk

**8. Named contact address**

Give the full institutional/organisational postal address for the named contact.

344a Watson Building, Brighton and Sussex Medical School, Falmer Campus, Village Way, Brighton, BN1  
9PH

**9. Named contact phone number.**

Give the telephone number for the named contact, including international dialling code.

07861240673

**10. \* Organisational affiliation of the review.**

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Brighton and Sussex Medical School

**Organisation web address:**

**11. \* Review team members and their organisational affiliations.**

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Dr Geoffrey Wells. Brighton and Sussex Medical School  
Dr Rebecca Winter. Brighton and Sussex Medical School  
Professor Carrie Llewellyn. Brighton and Sussex Medical School  
Professor Juliet Wright. Brighton and Sussex Medical School  
Ms Elaney Youssef. Brighton and Sussex Medical School

**12. \* Funding sources/sponsors.**

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

Brighton and Sussex Medical School

Grant number(s) or award number and the date of award

**13. \* Conflicts of interest.**

List actual or perceived conflicts of interest (financial or academic).

None

**14. Collaborators.**

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. NOTE: email and country must be completed for each person, unless you are amending a published record.

**15. \* Review question.**

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

- 1) What is documented in the literature about the confidence of medical students to care for a dying patient and their family?
- 2) Which qualitative and quantitative methods/tools have been used to measure medical student confidence in the context of caring for a dying patient?
- 3) Is there any evidence that medical student's confidence has changed over time?

**16. \* Searches.**

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

Embase, CINAHL, MEDLINE, PsycINFO, ISI Web of Science, ERIC, British Education Index, GREY, Education abstracts, and Cochrane review databases have been searched.

There were no restrictions on date

Searches were limited to English language and human studies only.

**17. URL to search strategy.**

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search results.

[https://www.crd.york.ac.uk/PROSPEROFILES/119057\\_STRATEGY\\_20181218.pdf](https://www.crd.york.ac.uk/PROSPEROFILES/119057_STRATEGY_20181218.pdf)

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

**18. \* Condition or domain being studied.**

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Undergraduate medical education

Confidence in caring for a dying patient and their family.

#### 19. \* Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Inclusion criteria:

- Undergraduate medical students
- Studies measuring confidence
- Studies involving the care of a dying patient
- Studies with full text availability (using 3 sources)

Exclusion criteria:

- Articles relating to only the care of general palliative patients (i.e. It must also look at the care of the dying/terminally ill if it is to be included)
- General end of life care
- Students from any discipline other than medicine
- Articles relating to an individual student's experience
- Any form of graduate training (including residency and internship)
- Letters or personal opinions
- Articles without abstracts
- Articles not in English language

#### 20. \* Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

Evidence suggests that many students graduating from medicine demonstrate a lack of confidence when asked to care for a dying patient, and yet they will be certain to look after many dying patients in their first year.

This review aims to identify what is written in the literature about student confidence to care for a dying patient and their family, and to ascertain how student confidence is being measured. It is hoped that the review will help identify tools that are currently and historically used to measure confidence, in either a qualitative or quantitative way.

#### 21. \* Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

In the event that confidence is measured pre and post intervention, only the pre-intervention measure will be

reviewed, in order to give a baseline measure without influence from the intervention itself.

Comparisons may be made (if data exists) between the outcome of studies published historically, to contemporary data.

Comparisons may be made (if data exists) of student confidence as seen between different years of study (e.g. Between 1st year medical students vs 5th year medical students).

#### 22. \* Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Review to include original data only, not data from other reviews.

Studies can be of any type (qualitative / descriptive / quantitative) providing they meet the above criteria.

#### 23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Studies will most likely have been undertaken in undergraduate medical school settings. Any such studies worldwide will be included.

#### 24. \* Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

- To understand whether student confidence in looking after a dying patient has ever been measured
- To identify which tools have been used to measure confidence in this context
- To identify any trends in medical student confidence with respect to looking after a dying patient, and whether trends have changed through time (if possible to compare older studies with newer ones).

#### \* Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.

#### 25. \* Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None.

#### \* Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.

#### 26. \* Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

All articles identified using the above search criteria and databases will be relocated into EndNote for de-duplication (primary reviewer)

Once this is done they will be transferred to an Excel spreadsheet and both the titles and abstracts will be screened to see whether they meet the basic inclusion criteria (primary researcher)

Detailed full text review of the identified articles will be undertaken by two independent reviewers for inclusion or exclusion into the final review. Any discrepancies with respect to inclusion of an article will be dealt with by asking a third independent reviewer to give their opinion as to whether it should be included or excluded.

All articles will be assessed using the above inclusion criteria, but specifically whether each article is:

- Pertaining to undergraduate medical students
- Measuring confidence
- Specifically looking at the care of a dying patient.

Any missing data will be requested from the authors of individual articles where possible, this will be carried out by the primary reviewer.

#### 27. \* Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Assessment of study quality will be carried out using the Mixed Methods Appraisal Tool (MMAT). This will be carried out by two to three reviewers independently, and inter-rater variability will be calculated.

#### 28. \* Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This must not be generic text but should be specific to your review and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

Given the likely heterogeneity of the studies, a narrative synthesis approach will be taken. This approach may be subject to change depending on the content and structure of the articles being reviewed.

Analysis of data will look at size of target population (medical students), year of study, levels of confidence in relation to caring for a dying patient, measurements of confidence.

We will report any publication bias, as well as the quality of the evidence within each study included.

**29. \* Analysis of subgroups or subsets.**

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

It may be, given that we are not limiting our search to any particular country or countries, that differences in confidence of medical students between countries may be observed.

**30. \* Type and method of review.**

Select the type of review, review method and health area from the lists below.

**Type of review**

Cost effectiveness

No

Diagnostic

No

Epidemiologic

No

Individual patient data (IPD) meta-analysis

No

Intervention

No

Meta-analysis

No

Methodology

No

Narrative synthesis

Yes

Network meta-analysis

No

Pre-clinical

No

Prevention

No

Prognostic

No

Prospective meta-analysis (PMA)

No

Review of reviews

No

Service delivery

No

Synthesis of qualitative studies

No

Systematic review

Yes

Other

No

Health area of the review

Alcohol/substance misuse/abuse

No

Blood and immune system

No

Cancer

No

Cardiovascular

No

Care of the elderly

No

Child health

No

Complementary therapies

No

COVID-19

No

Crime and justice

No

Dental

No

Digestive system

No

Ear, nose and throat

No

Education

Yes

Endocrine and metabolic disorders

No

Eye disorders

No

General interest

No

Genetics

No

Health inequalities/health equity

No

Infections and infestations

No

International development

No

Mental health and behavioural conditions

No

Musculoskeletal

No

Neurological

No

Nursing

No

Obstetrics and gynaecology

No  
Oral health  
No  
Palliative care  
Yes  
Perioperative care  
No  
Physiotherapy  
No  
Pregnancy and childbirth  
No  
Public health (including social determinants of health)  
No  
Rehabilitation  
No  
Respiratory disorders  
No  
Service delivery  
No  
Skin disorders  
No  
Social care  
No  
Surgery  
No  
Tropical Medicine  
No  
Urological  
No  
Wounds, injuries and accidents  
No  
Violence and abuse  
No

### 31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.  
English

There is not an English language summary

### 32. \* Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.  
England

### 33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository



(SRDR), details and a link should be included here. If none, leave blank.

#### 34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

**No I do not make this file publicly available until the review is complete**

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

#### 35. Dissemination plans.

Do you intend to publish the review on completion?

**Yes**

Give brief details of plans for communicating review findings.?

**The final review will form the first chapter of the primary author's MD thesis. In addition it is anticipated that this review will be submitted for publication.**

#### 36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

**Systematic review; medical student; confidence; care of the dying; medical education**

#### 37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

#### 38. \* Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing.

Please provide anticipated publication date

**Review\_Completed\_published**

#### 39. Any additional information.

Provide any other information relevant to the registration of this review.

**It has been noted that a review entitled 'An assessment of medical student's preparedness to manage end of life care and an appraisal of potential interventions to improve educational outcomes' is registered with Prospero, and is currently being undertaken.**

**However, we believe that our review differs significantly in several ways, as it specifically looks at measurements of medical student confidence to care for a dying patient (as opposed to the broader and**

more general term 'end of life care'). In addition we have placed no limitations on year, nor country of origin.

**40. Details of final report/publication(s) or preprints if available.**

Leave empty until publication details are available OR you have a link to a preprint. List authors, title and journal details preferably in Vancouver format.

Wells G, Youssef E, Winter R, et al. Medical student confidence in care of the dying and their family: a systematic review. *BMJ Supportive & Palliative Care* Published Online First: 09 January 2020. doi: 10.1136/bmjspcare-2019-001977

Give the link to the published review or preprint.

<http://spcare.bmj.com/cgi/content/abstract/bmjspcare-2019-001977>.

## Appendix D: STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies

	Item No	Recommendation	Page No
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	101
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	-
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	101
Objectives	3	State specific objectives, including any prespecified hypotheses	102
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	76
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	76
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	76-77
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	80
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	78
Bias	9	Describe any efforts to address potential sources of bias	78
Study size	10	Explain how the study size was arrived at	76
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	81-82

Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	81
		(b) Describe any methods used to examine subgroups and interactions	81
		(c) Explain how missing data were addressed	82
		(d) If applicable, describe analytical methods taking account of sampling strategy	81
		(e) Describe any sensitivity analyses	81-82
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	102
		(b) Give reasons for non-participation at each stage	103
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	104
		(b) Indicate number of participants with missing data for each variable of interest	103-1-4
Outcome data	15*	Report numbers of outcome events or summary measures	105-108
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	105-108
		(b) Report category boundaries when continuous variables were categorized	105-108
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-

Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	108-112
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	112-113
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	113
Generalisability	21	Discuss the generalisability (external validity) of the study results	112-113
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	-

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

## Appendix E: Adapted Thanatophobia Scale Questionnaire

Thank you for completing this questionnaire. By completing it, you consent to the data being used as part of the researcher's study. All data will be anonymous, and answers will have no effect on your training. This data will only be used as part of a postgraduate research study here at BSMS.

After completing the participant characteristic data, please mark on the scale of 1-7 how much you agree/disagree with each statement as honestly as possible.

Age (Years):

Gender identity:

Do you have a previous degree? YES / NO

	1	2	3	4	5	6	7
	Strongly Disagree						Strongly Agree
1. Dying patients make me feel uneasy							
2. I would feel pretty helpless having terminal patients on my ward.							
3. I would find it frustrating to have to continue talking with relatives of patients who are not going to get well.							
4. The thought of managing dying patients traumatizes me.							
5. It would make me uncomfortable if a dying patient wanted to say goodbye to me.							

6. I don't look forward to being the personal physician of a dying patient.							
7. If a patient began to discuss death, I would feel uncomfortable.							

Many thanks. Dr Geoffrey Wells (Primary researcher). Research Fellow, 344a Watson Building, BSMS. Email: [g.wells@bsms.ac.uk](mailto:g.wells@bsms.ac.uk)

## **Appendix F: Self-efficacy in Palliative Care (SEPC) Scale:**

### **Instructions and scale items**

The following statements relate to communication / patient management / multi-professional issues that may be encountered within palliative care.

Please answer the following questions by placing an 'X' on the line between 'very anxious' and 'very confident' in relation to how you think you would feel about:

#### **Communication:**

##### **Discussing the likely effects of cancer with the patient**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

##### **Discussing the likely effects of cancer with the patient's family**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

##### **Discussing issues of death and dying**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

##### **Discussing the patient's own death (with the patient)**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

##### **Discussing the patient's death (to occur) with the family**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|



**Discussing the patient's death with the family upon bereavement**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Answering the patient's question: "How long have I got to live?"**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Answering the patient's question: "Will there be much suffering or pain?"**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Patient Management:**

**Your ability to assess the patient's needs**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your knowledge of the aetiology of common symptoms experienced by palliative care patients**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your ability to manage common symptoms experienced in palliative care patients**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your ability to prescribe appropriate and adequate pain control medication**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your knowledge of the therapeutic and side-effects of analgesic agents**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your ability to provide psychological care for the palliative care patient and his or her family**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your ability to provide social care for the palliative care patient and his or her family**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Your ability to provide spiritual care for the palliative care patient and his or her family**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Multidisciplinary Teamworking:**

**Working within a multiprofessional palliative care team**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Appropriately referring palliative care patients for physiotherapy**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Appropriately referring palliative care patients for occupational therapy**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Appropriately referring palliative care patients for complementary therapies**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Appropriately referring palliative care patients to a lymphoedema service**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Appropriately referring palliative care patients for psychiatric evaluation**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

**Appropriately referring palliative care patients to a spiritual advisor**

Very anxious

Very confident

|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|

## Appendix G: COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	93-94
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	-
Occupation	3	What was their occupation at the time of the study?	-
Gender	4	Was the researcher male or female?	-
Experience and training	5	What experience or training did the researcher have?	-
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	93-94
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	93-94
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	n/a
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	83-84

<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	84-85
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	84-87
Sample size	12	How many participants were in the study?	85
Non-participation	13	How many people refused to participate or dropped out? Reasons?	-
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	93-94
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	n/a
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	84-85
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	93
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n/a
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	93-94
Field notes	20	Were field notes made during and/or after the inter view or focus group?	93-94
Duration	21	What was the duration of the inter views or focus group?	93-94
Data saturation	22	Was data saturation discussed?	93-94
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction	94-95
Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	95-96
Description of the coding tree	25	Did authors provide a description of the coding tree?	n/a

Derivation of themes	26	Were themes identified in advance or derived from the data?	131-143
Software	27	What software, if applicable, was used to manage the data?	96
Participant checking	28	Did participants provide feedback on the findings?	n/a
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	131-143
Data and findings consistent	30	Was there consistency between the data presented and the findings?	131-145
Clarity of major themes	31	Were major themes clearly presented in the findings?	131-145
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	n/a

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

## Appendix H: Simulation Timeline

### AM 09:00 – 12:30

09:00-09:30 (30 mins)	Welcome to simulation. Meeting the team. Housekeeping, health warning Outline of what the session will entail. 15-minute overview on symptom control in the dying patient (Consultant facilitator). Brief background to our simulated patient
09:30-09:55 minutes) (25 mins)	Scenario 1 (Prep 5 minutes/Simulation 10 minutes/Debrief 10
09:55 – 10:20 (25 mins)	Scenario 2
10:20 – 10:45 (25 mins)	BREAK
10:45 – 11:10 (25 mins)	Scenario 3
11:10 – 11:35 (25 mins)	Scenario 4
11:35 – 12:00 (25 mins)	Scenario 5
12:00 – 12:30 (30 mins)	Focus group
12:30 – 13:30	LUNCH AND CHANGEOVER

### PM 13:30 – 17:00

13:30-14:00 (30 mins)	Welcome to simulation. (As above)
14:00-14:25 minutes) (25 mins)	Scenario 1 (Prep 5 minutes/Simulation 10 minutes/Debrief 10

14:25 – 14:50 (25 mins)	Scenario 2
14:50 – 15:15 (25 mins)	BREAK
15:15 – 15:40 (25 mins)	Scenario 3
15:40 – 16:05 (25 mins)	Scenario 4
16:05 – 16:30 (25 mins)	Scenario 5
16:30 – 17:00 (30 mins)	Focus group
<b>17:00</b>	<b>END</b>



## **Appendix I: Simulation scenarios and scripts**

### **SCENARIO 1**

**(STUDENT) FY1 scenario 1:** You are the FY1 on call. One of the ward nurses has bleeped you and asked you to come and review one of their patients, Richard Walker, who has developed noisy, rattling breathing. Richard's next of kin is present at his bedside and is somewhat distressed by the noise. Please review the last entry in the patient's notes, and perform a focussed review of Richard's breathing. Please explain to the next of kin what you can do to help with the noisy breathing, and address any concerns they may have.

**(ACTOR) NOK script scenario 1:** – You are Richard's only sister/brother. You have been with him through all his previous admissions and he has always bounced back. You realise he is very unwell and although the consultant believes he is dying you are hopeful Richard will respond to current treatment.

You are concerned about Richard's increasingly noisy breathing. You are concerned that he is struggling and want to know what can be done about it. You are happy for the FY1 to examine Richard.

- 1) Once they have examined him you ask what they think is wrong and what they can do about it.

**During this scenario Richard will die** (facilitator will warn you when this is about to happen). You will notice he stopped breathing (if the FY1 hasn't already noticed – Geoff will prompt). You are understandably upset. This should be in proportion to the situation – you realise just how unwell he was.

- 2) You want to know if he suffered
- 3) You want to know if the medication had been given earlier for his breathing, whether you would have had more time with Richard.

It is hoped that the FY1's will offer you comfort, and reassurance that your brother did not suffer.

**Notes for Geoff:** Anticipatory medications will be prescribed on the drug chart, including glycopyrronium which will clearly be stated can be used for respiratory secretions.

**Notes for sim operator:** Respiratory rate: 8 breaths per minute, after 2 minutes reduce this to 6 breaths per minute.

Pulse 30 per minute, weak. Patient will die, Geoff will instruct when this will happen.

## **SCENARIO 2**

**(STUDENT) FY1 script scenario 2:** You are the FY1 on call. One of the ward managers has asked you to review a patient, Richard Walker, on the ward. The patient's next of kin has arrived on the ward and despite being updated by the ward nurse, she is asking to speak with a doctor. The next of kin feels Richard is in pain. He has a syringe pump with analgesia in place, and has not required any prn medications so far. Please perform a focussed review of Richard and speak with his next of kin.

**(ACTOR) NOK script scenario 2:** You have travelled a long distance to come and see your brother during this admission. You have not seen him for several months prior to this, you have a somewhat difficult relationship with each other. You know he has cancer and thought he did not sound well when you spoke a few weeks ago on the phone. You know he is in hospital with a chest infection, however Richard has never informed you of just how ill he has been. As a family you do not like to talk about illness, and remain focussed on positive aspects of life, and you expect that he will get better and go back home. You have arrived to see Richard today after a long journey from Cornwall, you are tired, and are shocked at how unwell he is. It is out of hours, and the main medical team have gone home.

- 1) You demand a chest x-ray to be performed now as you want to see how things are going. Initially you cannot accept he is dying and are in denial. You become angry, mostly at your brother for not telling you how unwell he is when you last spoke.

**Richard will remain alive through this scenario**

It is hoped that the FY1's will comfort you and reassure you he is not suffering, as the scenario progresses you can begin to start appreciating the irreversibility of the situation – this may depend on how reassured you feel by the F1.

**Notes for Geoff:** For this scenario a syringe pump and anticipatory medications need to be prescribed in advance. Ensure 'not for further investigations' is written in notes.

**Notes for sim operator:** Resp rate = 12, Pulse 60, crackles at base

### **SCENARIO 3**

**(STUDENT) FY1 scenario 3:** You are the FY1 on call. One of the ward nurses has bleeped you and asked you to review one of their patients, Richard Walker, who appears to be breathless. The nurse has noticed Richard's breathing had become more laboured and has administered a stat dose of sub-cutaneous morphine 30 minutes ago, as prescribed. A family member is present and has become distressed by this and would like speak with a doctor. There is no evidence the patient is distressed at all. Please review the last medical entry in the notes and perform a focussed review. Explain your initial management plan to the family member. Richard has a drug chart with anticipatory end of life medications prescribed.

**(ACTOR) NOK script scenario 3:** You are Richard's only sister/brother. You have been with him through all his previous admissions and he has always bounced back. You realise that Richard is very unwell and although the consultant believes he is dying you are hopeful that he will respond to treatment. You are concerned about your brother's breathing. Richard has not spoken a word for 24 hours, but you are concerned that his breathing rate has increased and would like a doctor to review him. You are happy for the FY1 to examine him.

- 1) Once they have examined him you ask what they think is wrong and what they can do about it.

**During the scenario Richard will die** (facilitator will tell you when this is about to happen). After Richard dies you are understandably upset.

- 2) You want to know if the morphine has 'finished him off', you've heard about this in the papers

**Notes for Geoff:** Anticipatory medications will be prescribed on the drug chart. For this scenario morphine prescription must be signed as having been given 30 minutes prior to scenario.

**Notes for sim operator:** Resp rate 18, with 10 second pause after every 10 breaths. After 3 minutes slow rate to 12, with 10 second pause after every 10 breaths. Pulse 30 per minute, weak. Patient will die – Geoff will instruct when this happens.

#### **SCENARIO 4**

**(STUDENT) FY1 script scenario 4:** You are the FY1 on the evening on-call shift. The ward nurse has asked you to come and speak with the family member of a patient who is concerned that we are no longer providing food or fluid for her brother, Richard. Richard has been reviewed daily by the medical team and they believe he is dying. He has been unable to eat or drink anything now for 48 hours. He is unconscious.

Please speak with the family member about their concerns, and carry out a focussed examination with a view to discussing provision of clinically assisted hydration.

**(ACTOR) NOK script scenario 4:** You have been involved in your brother's care for some time and have seen him deteriorate. You and your brother are practising Christians with a strong faith, this is very important to you both. One of the things that is important to you is the provision of food and water in times of sickness. You see that your brother is not very conscious, but you believe it is the lack of food and fluid that has led to this current situation. You have only just arrived this evening and missed the medical team who saw Richard earlier.

- 1) You remain convinced that by providing clinically assisted food and fluid your brother's condition will improve. Richard has not been able to drink anything for 48 hours.
- 2) You do not want him to dehydrate to death, and you want the doctor to start some additional fluids at the very least.

It is hoped the student will assess the patient to see whether additional fluids would cause any harm and develop a plan with you (which may involve the

provision of slow subcutaneous fluids). It is hoped the inappropriateness of clinically assisted nutrition will be discussed with you.

**Notes for Geoff:** It is hoped the student will offer the NOK to speak with a member of the chaplaincy team, but if not offered, prompt the actor to ask about this. Drug chart with anticipatory meds.

**Notes for sim operator:** Resp rate 12 per minute. Chest clear. Pulse 60.

## **SCENARIO 5**

**(STUDENT) FY1's script scenario 5:** You are the FY1 on call. One of the medical day teams handed over to you to review one of their patients, Richard Walker, who had experienced some pain earlier in the day. The team made some changes to his medications and Richard has remained settled for the past few hours. Listen to his chest and gently palpate his abdomen to ensure there is no build-up of respiratory secretions or abdominal pain. **This is a focussed examination not a full resp/GI examination.** You are assessing to see that patient is comfortable. Richard's next of kin is present at the bedside, and is anxious about what is happening. They have visited Richard twice daily for the past 2 weeks in hospital and is worried about what is happening.

**(ACTOR) NOK script scenario 5:** You have been visiting your brother twice daily for the past 2 weeks since his admission to hospital. You moved in to live with Richard 6 months ago when he was diagnosed with terminal cancer. You know that smoking is bad for him, and you feel guilty that you never insisted he stopped smoking. You have been buying cigarettes for him since he became house-bound 2 months ago. **During the scenario Richard will die** (facilitator will tell you when this is about to happen). When your bother dies in the scenario you are devastated. He means the world to you.

- 1) You feel incredibly guilty and blame yourself for his death. You do not have any other family.
- 2) You want to know if you had not bought the cigarettes whether he would still be alive now?

**Notes for Geoff:** Drug chart with anticipatory meds.

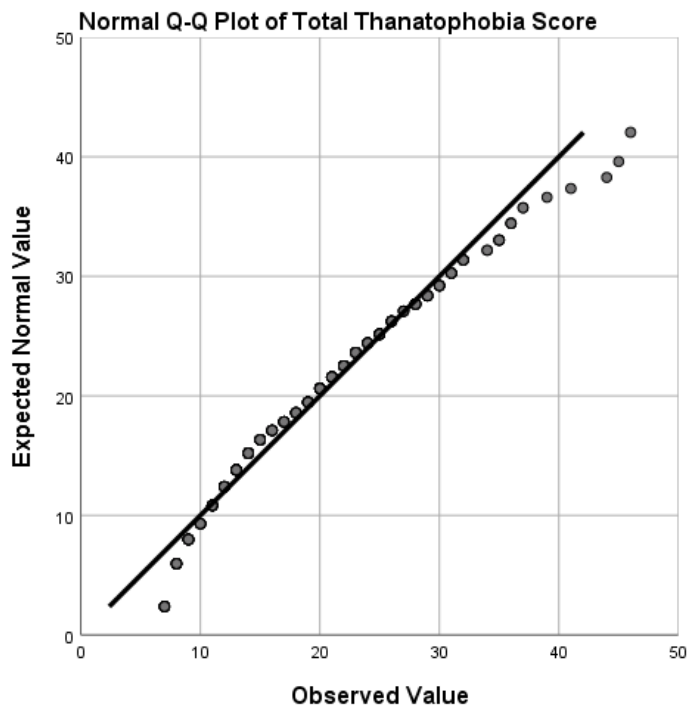
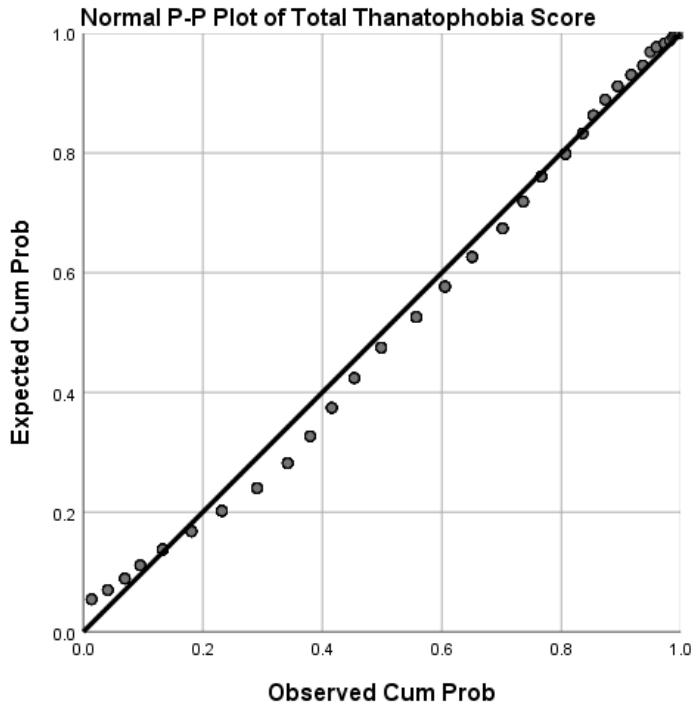
**Notes for sim operator:** Respiratory rate 12 with 10 second pauses after every 10 breaths. Pulse 40, weak. Patient will die, Geoff will instruct when this is to happen.

## **Appendix J: Focus group topic guide**

1. How do you feel having completed the simulations? Can probe a bit further
2. In what way do the simulations compare or differ to your experiences on clinical placements, be that on the ward or in the hospice?
3. Do you think the current undergraduate curriculum prepares you to look after dying patients and their relatives? Probe, alternative viewpoints?
4. What do you think are the advantages and disadvantages of these simulations?
5. If these simulations were to be adopted into the BSMS undergraduate curriculum, where in the curriculum do you think they would be best placed? (In terms of year/term)

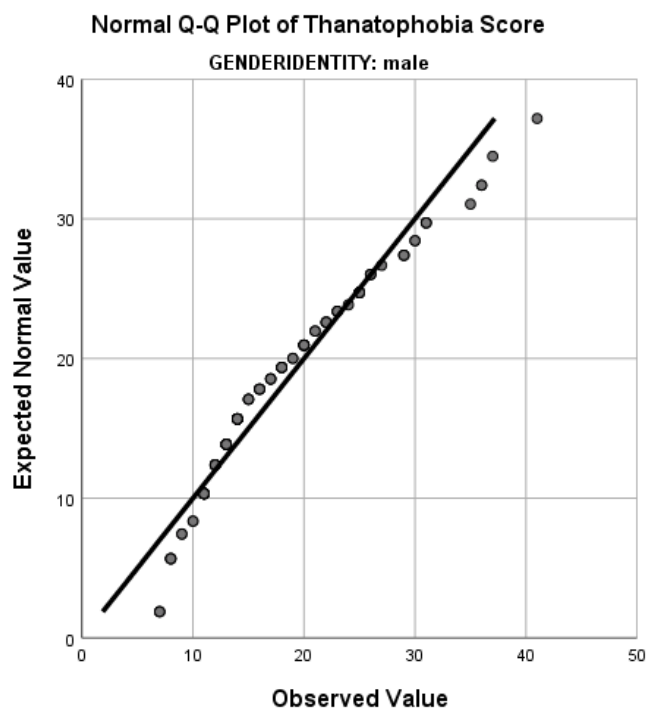
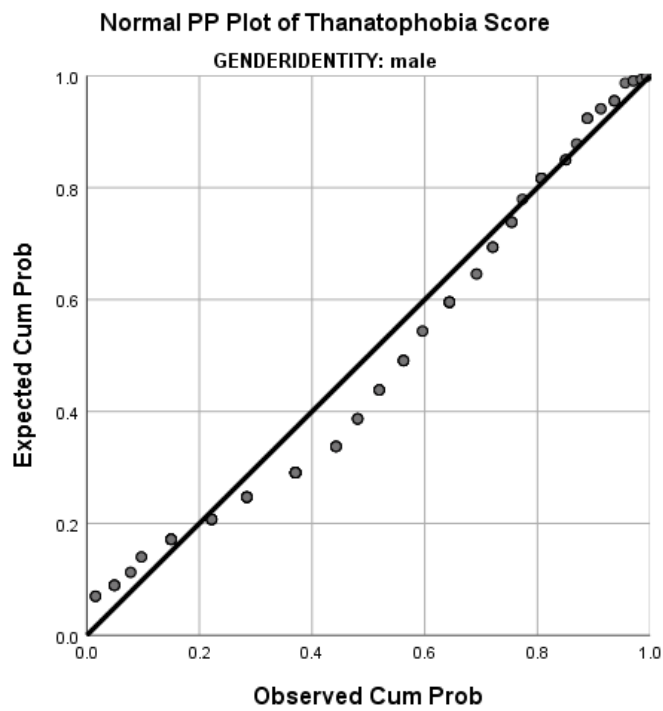
## Appendix K: PP and QQ plots of Thanatophobia Score variables.

### Overall Thanatophobia Scores

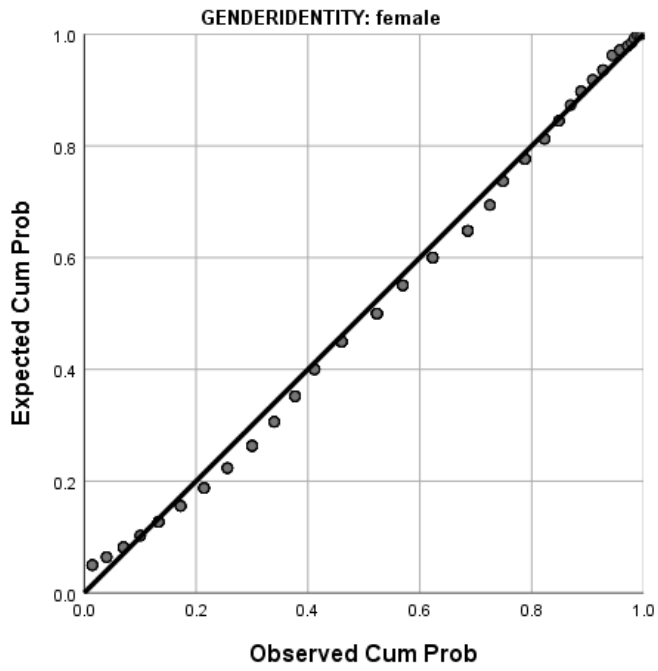




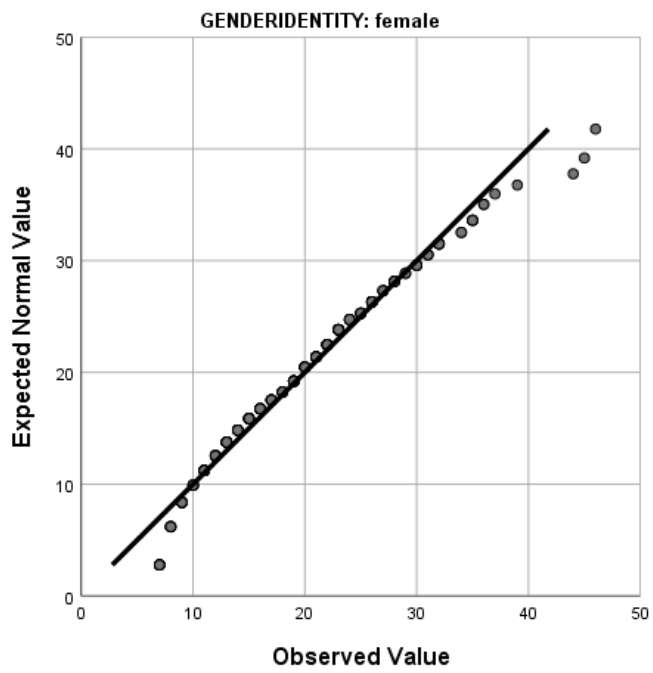
## Gender Identity



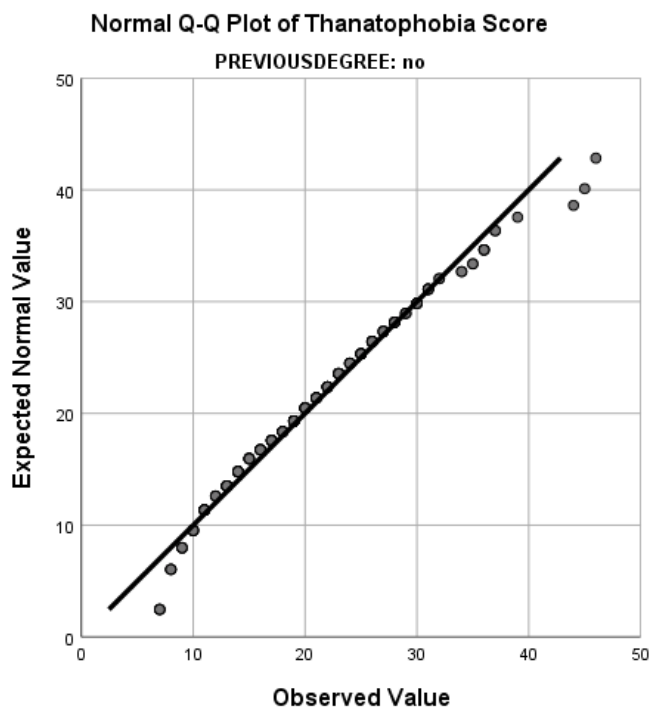
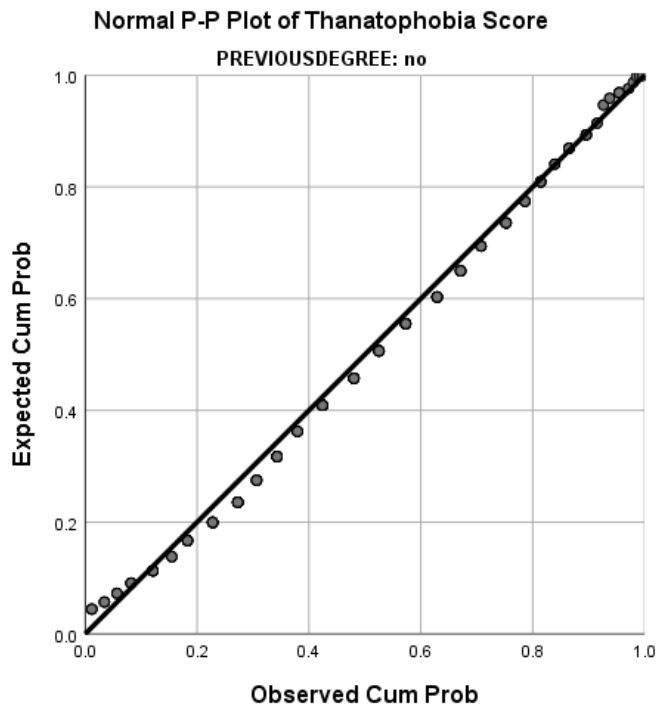
Normal P-P Plot of Thanatophobia Score



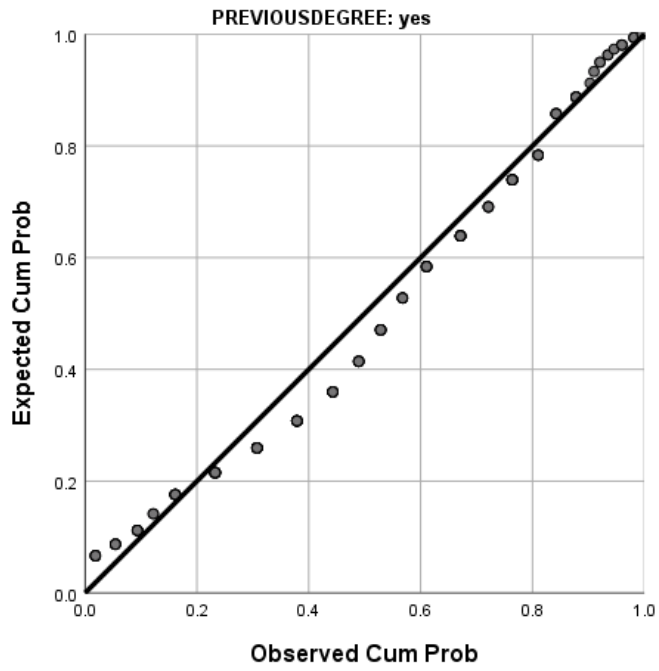
Normal Q-Q Plot of Thanatophobia Score



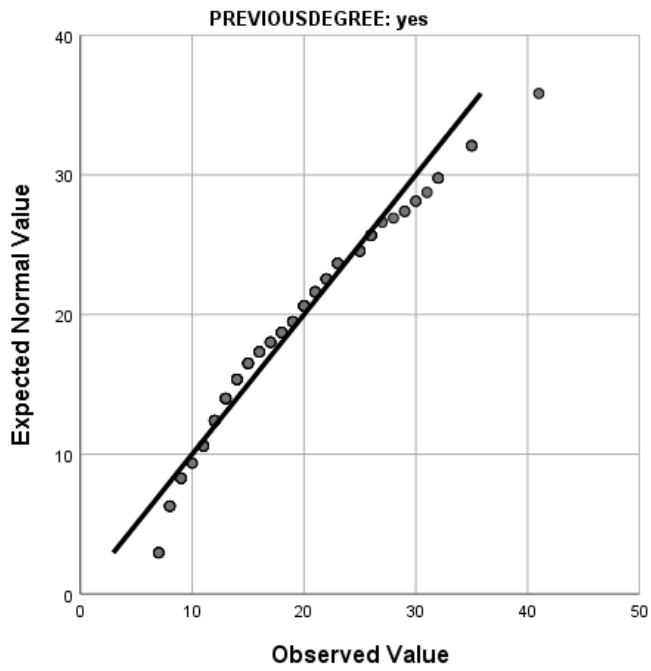
## Degree Status



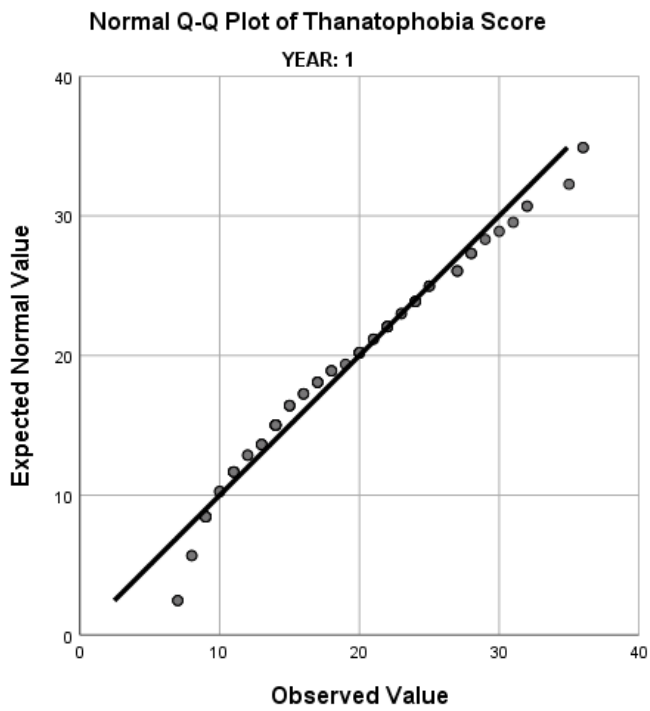
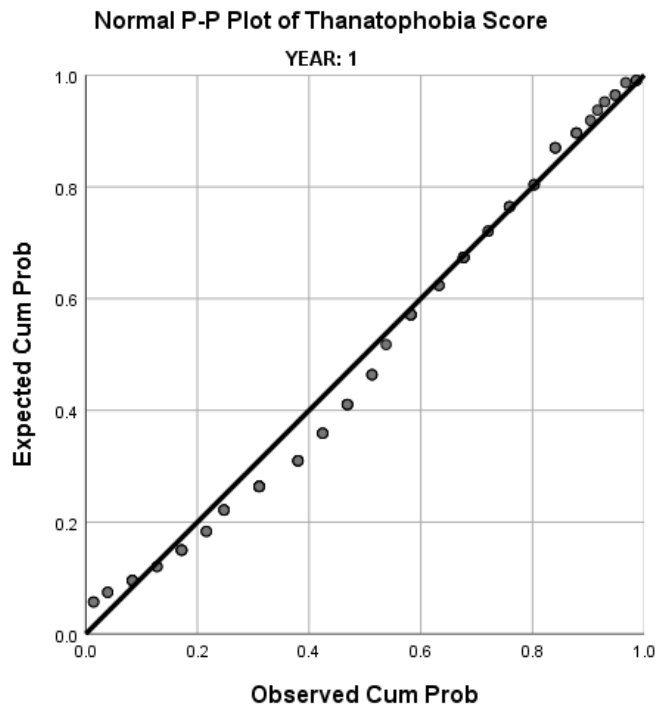
Normal P-P Plot of Thanatophobia Score



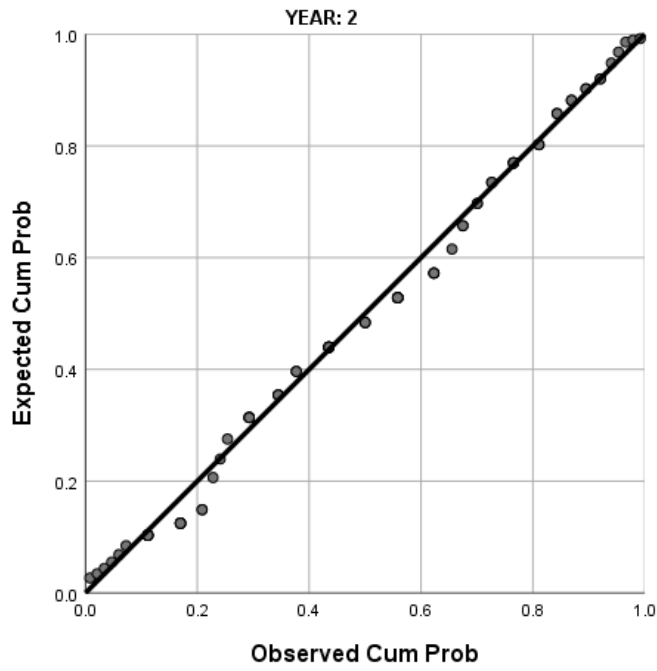
Normal Q-Q Plot of Thanatophobia Score



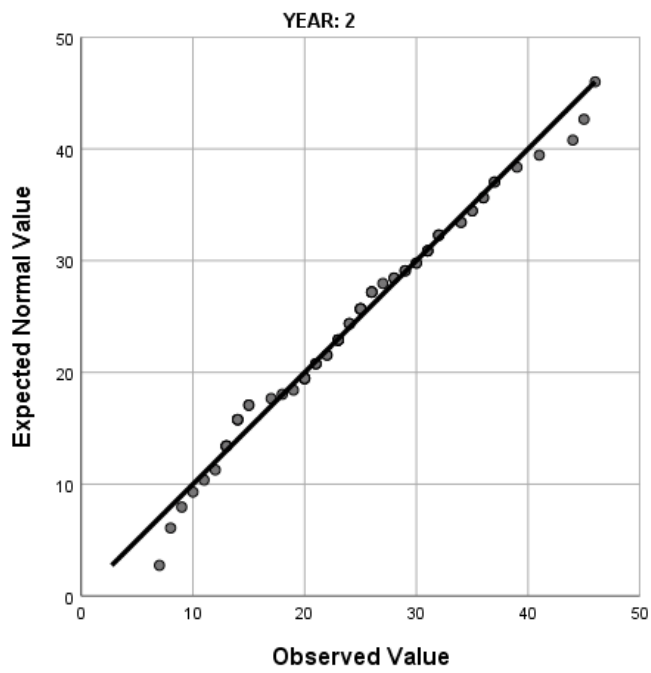
Year of Study



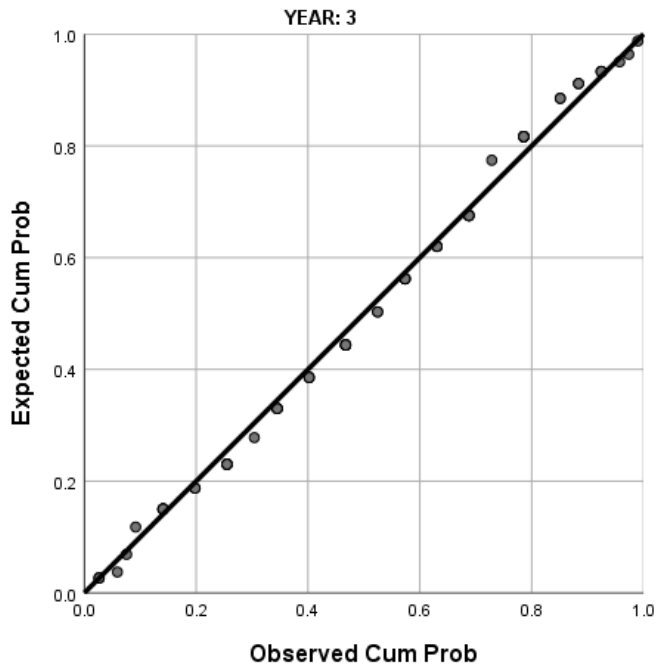
Normal P-P Plot of Thanatophobia Score



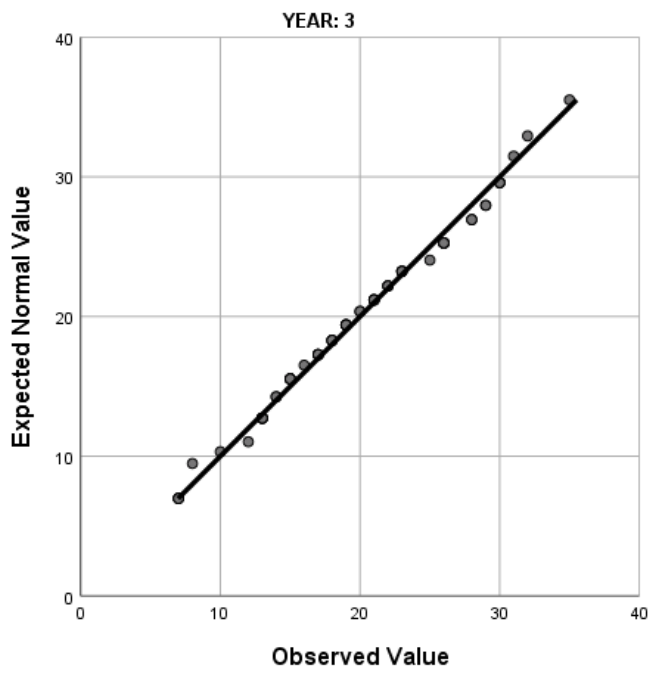
Normal Q-Q Plot of Thanatophobia Score



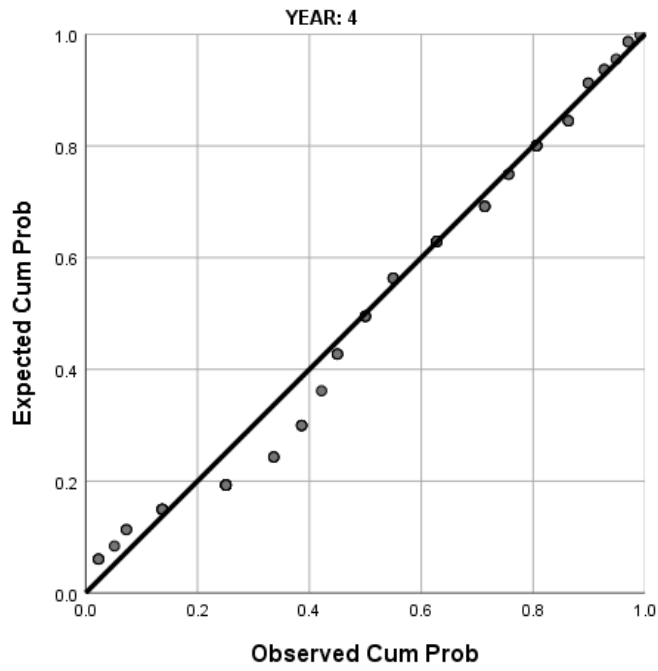
Normal P-P Plot of Thanatophobia Score



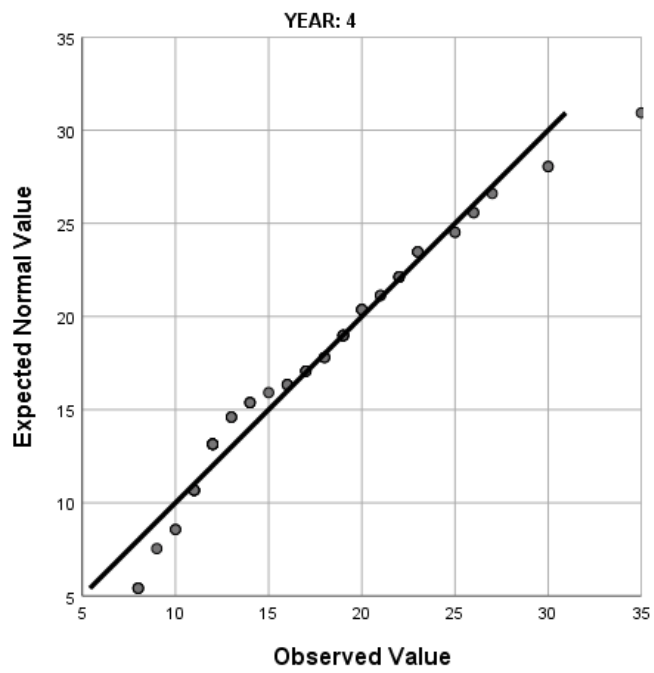
Normal Q-Q Plot of Thanatophobia Score



Normal P-P Plot of Thanatophobia Score

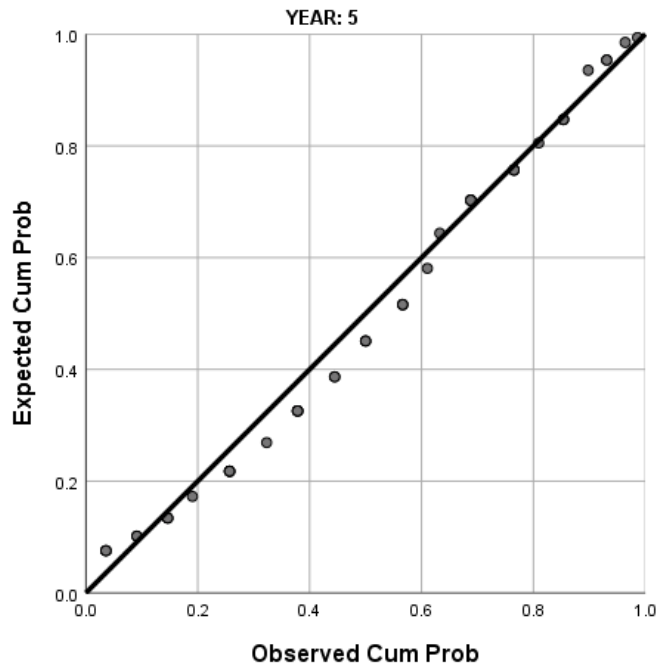


Normal Q-Q Plot of Thanatophobia Score

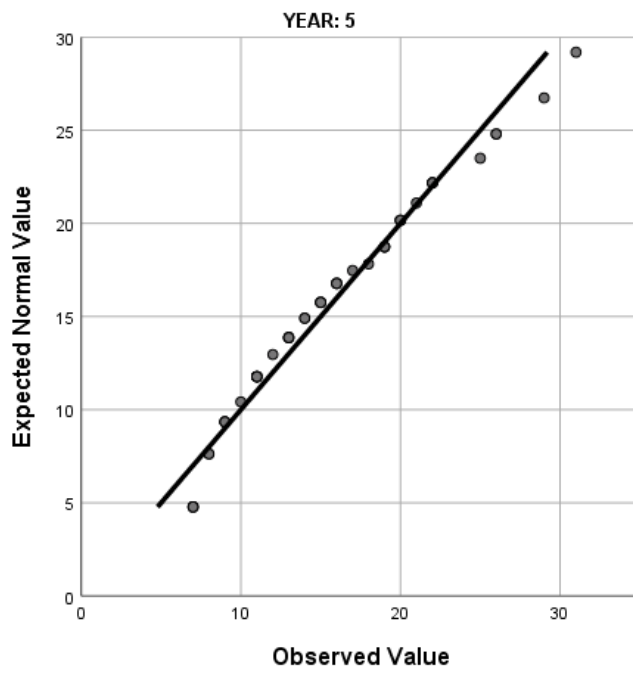




Normal P-P Plot of Thanatophobia Score



Normal Q-Q Plot of Thanatophobia Score



## Appendix L: Post-simulation Kolmogorov-Smirnov (KS) tests for SEPC data

### Immediately post-simulation data

	Mean	SD	Kolmogorov-Smirnov	
			Statistic	Significance
<b>Immediately post-simulation communication skills</b>	64.94	11.85	.111	p=.200
<b>Immediately post-simulation patient management</b>	63.49	13.16	.098	p=.200
<b>Immediately post-simulation MDT working</b>	56.11	15.46	.111	p=.200

### Six-months post-simulation data

	Mean	SD	Kolmogorov-Smirnov	
			Statistic	Significance
<b>Six-months post-simulation communication skills</b>	64.08	12.29	.098	p=.200
<b>Six-months post-simulation patient management</b>	66.23	14.63	.125	p=.150
<b>Six-months post-simulation MDT working</b>	66.85	14.18	.134	p=.091

## Appendix M: Covering letter for PPE



**Dr Geoffrey Wells**  
Research Fellow in  
Medical Education  
Room 204, Southpoint  
Paston Place  
Brighton, BN2 1HA

7<sup>th</sup> November 2019

Dear Dr

I am writing with regards to the research project I am undertaking as part of my Medical Doctorate entitled: ***Does simulated experience of caring for a dying patient and their family improve the confidence and preparedness of medical students?***

You kindly facilitated one of the simulated sessions earlier this year. Initial results are very encouraging with demonstration of statistically significant improvements in post-simulation confidence amongst participants. Six-month post simulation data also appears to show that this improved confidence is sustained.

An essential part of my research project is public and patient engagement (PPE). Patients and members of the public can often provide views that differ to that of researchers by virtue of their lived experiences of a particular subject matter. Such diversity of views can then be incorporated within research, facilitating increased level of grounding to discussions within research themes. I would therefore like to speak with a small number of recently bereaved relatives to seek their opinions on how they feel medical students could be taught to care for dying patients, and what their personal experiences of this may have been.

You kindly suggested that such a meeting could be arranged at St Wilfrid's Hospice, with support from your bereavement team. Any volunteer participants will be acting as expert advisors, providing their valuable knowledge of their experiences of the death of a close friend or relative in the context of medical student teaching. In the strictest sense this will not be regarded as research as volunteers will not be acting in the same way as a research participant. There will be no audio/video recordings made of any conversations, nor will any personally

identifiable data be documented. In my capacity as primary researcher I would be in attendance and would simply note down key phrases and sentences relating to any opinions and experiences participants may have in response to set questions I will ask. For these reasons formal ethical approval is not required.

Participation would be on a voluntary basis, and volunteers would be free to withdraw their participation at any time without any consequence to their ongoing support. I would like to thank participants for their involvement by providing them with lunch on the day.

Specifically, I would like to ask participants the following questions:

- Could you share your experiences of any student teaching you observed during your time visiting the hospice / hospital?
- How did you / would you feel about having students learn at the bedside of a dying relative/friend?
- What are your thoughts about the importance of medical students learning how to care for a dying person and their family?
- When thinking about increasing numbers of students on the wards / in the hospice, do you think there are alternative ways in which students could learn this?

I would be most grateful if you and your colleagues would formally consider my request. I would be happy to discuss details regarding the practicalities of dates and times with respect to a PPE meeting.

I look forward to hearing from you.

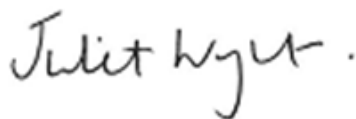
Yours sincerely

A handwritten signature in black ink, appearing to read 'G Wells', written over a light grey rectangular background.

**Dr Geoffrey Wells**

(Primary Researcher)

**Research supervisors**



**Professor Juliet Wright  
(Primary Supervisor)**  
Professor in Elderly  
Medicine  
Director of Undergraduate  
Teaching and Learning  
Brighton and Sussex  
Medical School



**Professor Carrie Llewellyn**  
Professor of Applied  
Behavioural Medicine  
Department of Primary Care  
Brighton and Sussex  
Medical School

## **Appendix N: PPE topic guide**

Thankyou

Put this meeting into context – I am researching medical student teaching, and specifically how we can teach them to care for a dying person. To improve their confidence and preparedness.

This is not bereavement session – am aware you may be receiving other support, I shan't be doubling up on that, but can speak with bereavement team if you would like further support.

**Ask who had been visiting a relative in the hospice, and who in the hospital.**

### **Junior doctors**

Can you tell me about your experiences of interacting with junior doctors whilst visiting the hospital or hospice?

Ask about confidence. Did they feel the Dr was prepared?

Hospital experience in general

### **Medical students**

During your time as a visitor to the hospice or hospital, were you aware of the presence of any medical students?

If you have had any encounters with medical students, can you describe your experience?

What was positive about the experience, where there any negatives about the experience?

### **Other students**

Have you noticed whether any other students were present e.g. Nursing students, physiotherapy students, pharmacy students?

Can you describe any encounters you had with them?

### **Last few days of life**

Were medical students present?

If yes – how did you interact with them. How did they interact with the person you were visiting?

### **Opinions regarding medical student teaching**

What are your views about medical students learning how to care for a dying person? Do they need to learn about it and how?

What are your thoughts about medical students being taught at the bedside of someone who is dying?

Can you think of alternative ways we could teach medical students to care for someone who is dying?

**Closing remarks and thank you** – write up and inform of your plans to send it to them.