PREPAREDNESS OF EMERGENCY CARE PROVIDERS TO DEAL WITH DEATH, DYING AND BEREAVEMENT IN THE PREHOSPITAL SETTING

A dissertation submitted in fulfilment of the requirements for the degree of Master of Health Science: Emergency Medical Care in the Faculty of Health Sciences at the Durban University of Technology

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DECLARATION OF ORIGINALITY

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

Name Reon Johnathan Conning

Signed _[redacted]

Date ____June 2018_________

ETHICAL CLEARANCE

This is to certify that the research studies conducted for the purposes of this dissertation have the approval of the Institutional Research Ethics Committee (IREC) of the Durban University of Technology (DUT) in KwaZulu-Natal.

Institutional Research Ethics Clearance Number: REC 134/17

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ABSTRACT

Introduction: Emergency care providers are exposed to events involving suffering and tragedy as part of their routine work in the field. They are accordingly expected to deal with death, dying and bereavement in a safe, sensitive, efficient manner, showing empathy and compassion while managing their own emotions. This can be stressful and lead to trauma symptoms, anxiety and depression.

Purpose: To investigate how prepared emergency care providers are to deal with death, dying and bereavement in the prehospital setting in order to recommend strategies that will diminish the emotional strain they experience, as well as decrease the trauma of sudden death and the number of abnormal grief reactions for the bereft.

Methods: The study used a quantitative descriptive prospective design. Data was collected using an online self-report questionnaire that was sent to all operational emergency care providers in the Dubai Corporation of Ambulance Services (DCAS). The data from consenting participants (n = 496) was analysed using the IBM Statistical Package for Social Sciences (SPSS) version 25.0. Inferential statistical techniques such as correlations and chi-square test values were used and interpreted using the p-values. Factor analysis was also conducted for the purpose of data reduction.

Results: The majority of respondents (n = 316; 64.4%) reported that they had not received any formal education or training on death, dying and bereavement. Those that had received formal education or training reported that this training was conducted mainly by nursing (n = 124; 25.9%) and paramedic (n = 65; 13.6%) instructors. A quarter of the respondents (n = 126; 25.4%) reported experiencing intrusive symptoms such as loss of sleep, missing work and nightmares as a result of a work-related death or dying incident, but only a few (n = 20; 4.1%) had received professional counselling.

Conclusion: This study found that emergency care providers are underprepared to deal with death, dying and bereavement and reported discomfort and anxiety associated with this aspect of their job. A comprehensive death education programme that encompasses the diversity of death and the unique challenges that the emergency and prehospital setting presents should be implemented to reduce emotional anxiety, help emergency care providers cope better with death and decrease the number of abnormal grief reactions on the part of the bereft.

DEDICATION

“Let life be beautiful like summer flowers and death like autumn leaves"

Rabindranath Tagore

This dissertation is dedicated to all the emergency and healthcare providers who have committed their lives to the service of others, notwithstanding the associated personal risks and sacrifices. In addition, the dissertation is also dedicated to their families and to the communities who provide these courageous individuals with essential support and to the dedicated professionals who provide them with the requisite training and education to prepare them to carry out their duties with pride and dignity.

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

GLOSSARY OF TERMS: OPERATIONAL DEFINITIONS

Akinetic mutism (locked in syndrome): medical term describing patients tending neither to move (**akinesia**) nor speak (**mutism**).

Assessment and intervention: the information gathered, decisions made, and actions taken by professional caregivers to determine and/or provide for the needs of persons who are dying, their loved ones, and bereaved individuals.

Bereavement: refers to the state of being bereaved or deprived of something. In the context of this study, bereavement identifies the objective situation of individuals who have experienced a loss of a person they value through death.

Clinical experience: refers to the actual observation and treatment of patients as opposed to the theoretical and/or basic sciences

Death: the ending of life; a permanent cessation of all vital functions, including brain function

Death anxiety: the morbid, abnormal, or persistent fear of one's own death

Death education: formal and informal methods for acquiring and disseminating knowledge about dying, death and bereavement

Declaration of death: a clinical assessment process undertaken to establish and document that death has occurred

Death notification: the delivery of the news of a death to someone

Dying: the physical, behavioural, cognitive and emotional experience of living with life threatening/life limiting illness, the dying process, and the experience of death

Emergency care: refers to the evaluation, treatment and care of an ill or injured person in a situation in which such emergency evaluation, treatment and care are required and the continuation of treatment and care during the transportation of such person to or between health establishments

Emergency care provider: a practitioner who provides emergency care treatment to patients in need of urgent medical care

Emergency medical service: refers to an organisation or body that is dedicated, staffed and equipped to operate an ambulance, medical rescue vehicle or medical response vehicle in order to offer emergency care

End-of-life decision making: the medical, legal, ethical and interpersonal choices, decisions and behaviours of individuals, families and professionals as life nears its end – often associated with a terminal illness

Loss, grief and mourning: the physical, behavioural, cognitive, and emotional experience of and reactions to loss, the grief process, as well as the rituals and practices surrounding grief

Prehospital: refers to any location outside of the hospital setting with limited or no medical resources

Preparedness: In this study, preparedness comprises a complex description of the knowledge, attributes and skills possessed by an individual to enable them to deal with death, dying and bereavement. It may be used in both a personal and a professional context.

Thanatology: derived from *thanos*, the Greek word for ‘death’, and *ology*, a science or organized body of knowledge. Thanatology therefore refers to the scientific study of death and the practices associated with it, including the study of the needs of the terminally ill and their families.

Traumatic death: a death that occurs in a manner that is unanticipated, shocking, or violent. Such a death may be inflicted, self-inflicted or unintentional.

Operational preparedness: the state of being able to deal with the challenges of the work environment. These challenges may differ from those encountered as academic and clinical cases during training.

ABBREVIATIONS

ADEC	Association for Death Education and Counselling
AFN	Artificially supplied Fluid and Nutrition
AHA	American Heart Association
CDC	Centre for Disease Control and Prevention
CISD	Critical Incident Stress Debriefing
CME	Continuing Medical Education
CPG	Clinical Practice Guideline
CPR	Cardiopulmonary Resuscitation
DCAS	Dubai Corporation of Ambulance Services
DCD	Donation after Cardiac Death
DDR	Dead Donor Rule
EDECT	Emergency Death Education and Crisis Training
EMT	Emergency Medical Technician
FWR	Family-witnessed Resuscitation
GRIEV_ING	Gather, Resources, Identify, Educate, Verify, _ space, Inquire, Nuts and bolts, Give
ILCOR	International Liaison Committee on Resuscitation
LST	Life Sustaining Treatment
MICA	Medical Intensive Care Ambulance
NAC	National Ambulance Company
OHCA	Out-of-Hospital Cardiac Arrests
PVS	Persistent Vegetative State
ROSC	Return of Spontaneous Circulation
SEGUE	Set stage, Elicit information, Give information, Understand their perspective, End

SPIKES	Setting, Perception, Invitation, Knowledge, Emotion/Empathize, Strategy/Summary
TOP	Temporary Organ Preservation
TOR	Termination of Resuscitation
UAE	United Arab Emirates
UDDA	Universal Determination of Death Act

CHAPTER 1: INTRODUCTION

1.1 CHAPTER OVERVIEW

This chapter introduces the study by providing the background to the study, presenting the research problem, research aim and research objectives, highlighting the researcher’s interest in the study topic and summarising the dissertation structure.

1.2 STUDY BACKGROUND

Death may be simply defined as the end of life, while dying is the process of approaching death (Lehman and Phelps, 2005). However, the simple truth that we will all die one day is often avoided and, as a result, some people may find themselves unprepared when faced with death.

Healthcare professionals may be unprepared for the death of their patients. Dealing with death, dying and bereavement is a complex process that requires training, education, psychological resilience, strategies for self-care and timely support. Healthcare workers must also manage their own death related feelings. Those healthcare workers who are underprepared may suffer acute or chronic stress which may lead to the development of cardiovascular diseases, post-traumatic disorders, sleeping disorders and obesity (Regehr, Goldberg and Hughes, 2002: 505).

In the prehospital setting, deaths may be unexpected and traumatic and can occur in unpredictable and uncontrolled environments. A study conducted among firefighters and paramedics listed exposure to death as a duty-related incident stressor (Beaton et al., 1998: 823). Emergency care providers are exposed to death, dying and bereavement as an integral part of their job. Prehospital emergency care providers are expected to carry out resuscitation on patients without spontaneous circulation, declare death, deliver death notifications, carry out the standard operating procedures to deal with the corpse, interact with a patient who is terminally ill and dying, and/or witness the reactions of families to the loss of their loved one. The way an emergency care provider deals with this aspect of their job may impact on the grieving process of the people who have experienced the loss, while the exposure to death and dying may have an impact on the emergency care provider.

Prehospital emergency care in Dubai is provided by the Dubai Corporation of Ambulance Services (DCAS). The emergency care providers who work for DCAS are mostly expatriates from all over the world. The mix of cultures, education and training backgrounds of these emergency care providers provides an opportunity to explore the issues surrounding preparedness to deal with death, dying and bereavement from these different perspectives.

1.3 RESEARCH PROBLEM AND AIM

Even though emergency care providers are exposed to death, dying and bereavement as part of their routine work in the field, little is known about their state of preparedness to deal with this important aspect of their job. Each of these phenomena are individually complex and profound and may affect people differently.

The aim of this study is to investigate how prepared emergency care providers are to deal with death, dying and bereavement and to make recommendations in order to enable emergency care providers to cope with these issues in a sensitive and efficient manner in the prehospital environment.

1.4 RESEARCH OBJECTIVES

This research study sought to

- investigate the educational and professional preparation of the emergency care provider with regard to death, dying and bereavement
- ascertain the emergency care provider's attitude towards death, dying and bereavement
- investigate the personal attributes of the emergency care provider that contributes to their preparedness to manage death, dying and bereavement in the prehospital setting
- make recommendations to enhance the knowledge and skills required by emergency care providers to deal with death, dying and bereavement.

1.5 THE RESEARCHER'S INTEREST IN THE STUDY

At the time of the study the researcher had been an emergency care provider for the previous 21 years and had worked at various clinical levels and in different aspects of prehospital and in-hospital emergency care. He is an Advanced Life Support emergency care provider who has spent the last 14 years in tertiary emergency care education and, at the time of the study, was the Head of the Emergency Medical Services Department at the largest tertiary institute in the United Arab Emirates. The researcher had acquired all his clinical experience in Durban and Cape Town, South Africa where he had extensive experience of death and dying, which was often violent and untimely. The researcher had also conducted numerous conversations during which people had acknowledged the extreme nature of the job and highlighted the need for emergency care providers to be highly trained to enable them to deal with all of the trauma that they encounter. There is also an implication that emergency care providers are, in some way, better prepared than the average person to deal with the situations that they face in their jobs. This notion is perpetuated externally by the brave, heroic images portrayed in the media and internally by ‘peer pressure’ within the profession. The researcher reflected on his own experience and career and developed an interest in investigating the preparedness of emergency care providers to deal with death, dying and bereavement.

1.6 DISSERTATION STRUCTURE

Below is an overview of the remaining chapters in this dissertation.

Chapter Two provides an extensive overview of the existing literature on death, dying and bereavement as it applies to healthcare providers and, in particular, to emergency care providers. The survey of relevant published works is intended to contextualise the study and provide the reader with a broad theoretical framework from which to approach the study. The strategies employed to identify, retrieve and extract relevant literature are also discussed.

Chapter Three outlines the research methodology and research design used in the study and includes a description of the study setting, the techniques used to collect and analyse the requisite data as well as an explanation of the ethical considerations which were taken into account while the study was conducted.

Chapter Four presents the findings obtained from the questionnaires which were administered in the study. The results are presented using descriptive statistics in the form of graphs, cross tabulations and other figures for the quantitative data that was collected. Inferential techniques include the use of correlations and chi square test values; which are interpreted using the p-values.

Chapter Five discusses the results of the study and links the findings with the study's research objectives in order to provide a broad, but in-depth, perspective of the research topic.

Chapter Six concludes the study by presenting a summary of the study, the implications of the study, recommendations for implementation, the limitations of the study and recommendations for future research.

The dissertation followed a generally accepted standard format consisting of logical divisions and order. The structure of the dissertation aimed to guide the reader through the topics of discussion in a naturally progressive manner in an attempt to ensure ease of reading and clear understanding.

A list of the references used, annexures and other supporting material are included at the end of the dissertation.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The scholarly activity in the “field of death studies – an umbrella term for the research spanning all aspects of death, dying and bereavement, including end-of-life care” (Borgstrom and Ellis, 2017: 93) is extensive and spans multiple disciplines over an expanse of time.

As early as 1917, during the infancy of psychoanalysis, Freud proposed one of the first theories on the process of grief and mourning (Walter, 1994). While it is considered prudent to review the most current evidence when conducting a literature review, some of the seminal works in this field date as far back as the 1960s, 70s and 90s. Glaser and Strauss (1965) and Elizabeth Kubler Ross (1969) continue to be regularly cited in research, teaching and professional education today (Borgstrom and Ellis, 2017: 93). Much of the more contemporary medical research is related to curative measures and extension of life, with a focus on preventive medicine (Williams et al., 2001: 130).

This literature review is intended to report objectively on the available body of knowledge on the topics of death, dying and bereavement as it pertains to healthcare workers and, in particular, emergency care providers, while placing the research problem in context and providing a theoretical framework for the research problem. A further purpose of this literature review is to identify gaps in the existing research and to rationalise the significance of this study.

The Association for Death Education and Counselling (ADEC) – the Thanatology Association – is one of the oldest interdisciplinary professional organisations. Thanatology (derived from *thanos*, the Greek word for ‘death’, and *ology*, a science or organised body of knowledge) has become so vast that, in 2005, a body of knowledge committee was formed. This committee identified the following six categories which are considered fundamental to thanatology, namely, Dying; End-of-life decision making; Loss, grief and mourning; Assessment and intervention; Traumatic death; and Death education (Meagher and Balk, 2013: ix).

Each one of these categories is multifaceted and may be viewed from various perspectives, including the cultural, religious, professional, historical and legal aspects. ADEC lists 10 indicators that intersect with each of the six categories mentioned above to form the Body of Knowledge Matrix (Table 2.1). This matrix illustrates the breadth and complexity of the field of thanatology while acknowledging that ‘no person can ever know all there is to know in this complex field’ (Balk et al., 2007: xi). The matrix provides a useful theoretical framework which may be used as a basis from which to approach the topic of the preparedness of emergency care providers to deal with death, dying and bereavement. However, despite this vast body of knowledge, the majority of people are unprepared to deal with unexpected death or terminal illness and dying (Brady, 2013: 625).

Table 2.1 Body of knowledge matrix

Indicators/ categories	Dying	End-of-life decision-making	Loss, grief, & mourning	Assessment & intervention	Traumatic death	Death education
Cultural/ socialisation	perspectives on dying, health care interactions, family roles	advance care planning, ethnic issues, values and attitudes, gender	factors affecting experience of and expression of grief, impact on mourning practices	advance care planning, cultural competence, communication, meaning of death	cause of death, meaning making, advance care planning, ethnic issues, values and attitudes, gender	different death systems, diverse views about death
Religious/ spiritual	facing death, rituals, meaning, suffering, impact on treatment decisions, afterlife, legacies	advance care planning, values and attitudes, beliefs and doctrines, suffering, sanctity of life, quality of life	meaning making, impact on mourning practices	components of spiritual assessment, interventions, facilitating integration of meaning and value of one's life	meaning-making, rituals, impact of religion	diversity of religious beliefs, diversity of meaning making, diversity of spirituality
Professional issues	Self-care, boundaries, compassion fatigue, burnout, attitudes toward dying	Communication, understanding patient's rights	burnout, compassion fatigue, awareness of personal loss history, coping strategies, self-assessment, self-care, boundaries, clinical competency	appropriate components of assessments, communication, professional liability and limitations, determining appropriate interventions in concert with evidence and client characteristics, professional responsibilities	appropriate training, professional response, commemorative activities, vicarious traumatisation	evaluation of knowledge, criteria for an effective educator, methods, training specific to parameters of practice, media and internet

Table 2.1 cont’d

Indicators/ categories	Dying	End-of-life decision-making	Loss, grief, & mourning	Assessment & intervention	Traumatic death	Death education
Historical perspectives	hospice, causes and patterns of death in Western societies, influential theories	landmark legal cases, attitudes toward final disposition, evolution of advance care planning	influential theories, post-death activities	changes in determination of death, intervention theories prior to 1990	previous major traumatic occurrences	attitudes towards death, history of thanatology as a discipline, historical eras
Contemporary perspectives	global causes and patterns of death and lifestyle choices, gender issues, impact of technology, influential theories, death attitudes, role of complementary /alternative therapies	options and choices, impact of medical technology, impact of media and internet	influential theories and models, post-death practices, media and internet, intervention strategies	current assessment models, current therapeutic strategies, controversy about efficacy of interventions, complicated grief, gender considerations, pathologising of grief	recent/ anticipated future traumatic occurrences, impact of communication systems, organ and tissue donation, current approaches	advance care planning, influence of media and the internet, social concerns, components of death education
Life span	normative developmental tasks, developmental concepts of death, special populations	impact of age on decision-making, determining competency to make decisions	impact of developmental stage on loss experience, specific types of loss and impact on grief and mourning	developmental considerations	death patterns, issues specific to each developmental phase	teaching across the life cycle, issues specific to each developmental phase, impact of life transitions
Institutional/ societal	hospice, palliative care, impact of politics, interacting with the healthcare system, special populations	advance care planning, health care legislation, public/mass media and political impact on decision-making	media and internet, school/work-place grief, public deaths, political systems	impact of death system, impact of societal infrastructure, contributions of grief support services	meaning making, role of the media and internet, infrastructure, types of traumatic deaths, impact on specific populations	influence of media and internet, varied educational settings, impact of larger systems, military
Family & individual	gender roles, communication, cultural impact on family roles, family history, coping strategies	advance care planning, treatment decisions, communication, family systems	family life cycle, communication, impact of illness trajectory, grief styles, normative grief responses, impact of type of loss	family systems theory, gender issues, assessment of risk factors for complicated/ prolonged grief, determining appropriateness of specific interventions	impact on experience of grief, types of traumatic deaths, coping strategies, individual differences, vicarious traumatisation, social support	formal, informal

Table 2.1 Body of knowledge matrix (cont'd)

Indicators/ categories	Dying	End-of-life decision-making	Loss, grief, & mourning	Assessment & intervention	Traumatic death	Death education
Resources & research	current significant research findings, organisations and journals, media and internet	media and internet, professional organisations, current significant research findings	empirical research on current theories, research on effectiveness of intervention	evidence of effectiveness of assessment and intervention, community programs	major national organisations, current significant research findings	types of resources, understanding the research, importance of evidence-based practice, certification, professional organisations
Ethical/legal	allocation of resources, ethical principles, legislation/ medical practice	principles of medical ethics, advance directives, landmark cases, legal planning, decision-making processes	ethics and working with the bereaved, legal aspects of death	determination of death, informed consent, ethical principles, legal parameters around death, professional responsibilities	criminal justice system, impact on larger society, ethical intervention issues	impact of legal system on death, understanding a professional code of ethics, applying principles of ethic

Source: Meagher and Balk, 2013

In this chapter the researcher endeavours to conduct an effective literature review by first describing in detail the strategy that was employed to search, critique and synthesise the available literature (Baker, 2016: 265) in order to establish the validity and relevance of the literature to the study and then, using the funnel technique, discussing the various topics that were deemed pertinent to the research problem. The funnel approach provides the structure for the literature review which will start with broad areas of discussion on dying, death and bereavement and become more specific to healthcare professionals and finally to emergency care providers.

2.2 LITERATURE SEARCH STRATEGY

The initial strategy to identify, retrieve and extract relevant literature involved the use of the online search engines of Google and Google Scholar and utilising a broad search of the keywords death, dying and bereavement. This yielded extensive search results – approximately 1 150 000 results (0.76 seconds). The first links that came up in the results were the publishing houses Sage Publishers and Springer Publishing Company. Both of these offered a vast list of resources which included books, journals, digital products, reference books and catalogues across various disciplines. These sites also cited a list of journals related to topics on death, dying and bereavement. This led to a refinement of the search within the disciplines of psychology, sociology and medicine. Other sites, such as www.dyingmatters.org, which contain scientific and non-scientific material for the purpose of raising an awareness of death, dying and bereavement also emerged. Using blogs, discussion boards and forums the site www.dyingmatters.org, hosts both professionals in the field of death, dying and bereavement, as well as anyone who is experiencing death, dying or bereavement or has an interest in the topic. The researcher was introduced to new themes and terms which were then included in the keywords and terms used in subsequent literature searches.

These searches involved accessing multiple online databases through the Higher Colleges of Technology library site and included:

- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- MEDLINE
- Health and Medical Complete
- Nursing and Allied Health Source
- Psychology Journals
- PubMed Central
- ProQuest

I was also able to access EBSCOHost through the Mohamed Bin Rashid University of Medicine and Health Sciences. This enabled me to access full journal articles from the peer-reviewed journals *Death Studies*, *Omega – Journal of Death and Dying* and *Mortality*. Using numerous medical subject headings (Mesh terms) I was able to access both quantitative and qualitative studies in this area together with multiple literature reviews, including key book reviews.

The search strategy was refined to include specific keywords and the Boolean operators AND, OR and NOT to allow for broad reading and depth. Examples included, but were not limited to the following:

- Death
- Death AND Dying
- Dying

- Death AND Bereavement
- Dying AND Bereavement
- Grief
- Bereavement
- Death Anxiety
- Death Competence
- Death Attitude
- Death Notification
- Death AND Healthcare Providers
- Death AND Paramedic OR Emergency Care Practitioner
- Sudden OR Unexpected Death
- Traumatic Death
- Death AND Physician
- Physician AND Death Notification
- Palliative Care AND OR Hospice Care
- End–of–Life Care
- Good AND Death
- Family Witnessed Resuscitation
- Coping AND Coping Strategies AND Emergency Care Providers OR Paramedics
- Emotional Labour
- Emotional Competence
- Death Trajectories
- Termination of Resuscitation
- Declaration of Death
- Death AND Dying AND Bereavement

- Post-Traumatic Stress Disorder
- Suicide AND Suicidology
- Depression
- Thanatology
- Simulation AND Death Education
- Death Education AND Curricula
- Grief Theories

The literature review had been ongoing since 2015 and no date range limit was used to allow for a clear historical perspective. The researcher joined Researchgate at www.researchgate.net. This is a community of researchers who share knowledge, experience, relevant articles and literature. This provided further literature for review purposes as well as a forum in which to discuss research methods and topics. Some foreign language articles on the topics of death, dying and EMS were sent to me by members of the forum. However, only articles that were available in English were reviewed.

Specific literature was selected and the abstracts were reviewed to assess for relevance, strength of evidence, size of study, and general interest in topics related to the research problem and to this study. Available complete articles were downloaded onto a hard-drive and a hard copy was printed for detailed reading. The reference lists of retrieved articles were also scanned for any other relevant articles. Secondary sources were identified, and the citation and reference were used to access the primary source for inclusion in the literature review.

Grey literature such as policy documents, conference presentations, and clinical practice guidelines also provided a valuable source of material which was included in the literature review. In addition, four related dissertations (3 PhD and 1 MSc) were downloaded, printed and reviewed. Two of the PhD studies had been conducted in the nursing discipline and completed at the University of KwaZulu-Natal and University of Cape Town, while the other PhD and the MSc dissertations had been conducted in Emergency Medical Care at the University of Maryland Baltimore and the University of Cape Town respectively.

Two key texts on death, dying and bereavement were also identified and purchased for the purpose of the literature review. *Handbook of thanatology: The essential body of knowledge for the study of death, dying and bereavement* (2nd edition), and *Death & dying, life & living* (7th edition) are prescribed texts for several death education programmes, courses and degrees.

The Higher Colleges of Technology recently purchased ProQuest E Books which allow full online access to books which were then searched using some of the keywords mentioned earlier.

Although the review of this vast body of knowledge yielded a wide range of literature across many disciplines, as Lerner et al. (2007) pointed out, there is a definite need to fill the void in areas of EMS research which focus primarily on clinical studies. The management of this significant number of references was undertaken using Mendeley Research Management Software which is produced by Elsevier.

Once the literature had been selected and evaluated, a set of headings and subheadings were selected to form the framework in which the synthesis and construction of the literature review would be conducted. This chapter reviews relevant literature on dying, death and bereavement and how this relates to healthcare providers in general and, more specifically, to emergency care providers. In addition, the chapter also explores the concept of preparedness through death education and death competence.

2.3 DYING

Dying is as much a part of life as is living. In a sense, we are all moving towards death and, thus, we all could be said to be dying. A useful definition of dying is “the physical, behavioural, cognitive and emotional experience of living with life threatening/life limiting illness” (Meagher & Balk, 2013: 33). In the context of this study, dying refers to the time in a person’s life when that person develops a fatal condition, when it is recognised by a physician, when knowledge of that condition is communicated to the person involved, when the person realises and accepts the facts of his or her condition, or when nothing more may be done to reverse the condition or preserve life (Kastenbaum, 2009: 97). Corr and many other thanatologists emphasise the fact that the dying person is still living and is continuing to experience a broad range of needs, desires, plans, projects, joys, sufferings, hopes and anxieties (Kastenbaum, 2009; Corr, Corr and Bordere, 2013; Meagher and Balk, 2013).

This section of the chapter examines attitudes related to dying such as death anxiety, death denial, death avoidance, fear of dying, and death acceptance. In addition, some of the current theories of dying are reviewed while the concept of dying a “good death” and end of life care are also explored.

2.3.1 Attitudes Toward Dying

Attitudes about death are constantly changing while there are also variations between nations and cultures (Auger, 2007; Brady, 2014: 37). In Western societies medical science has advanced to a point where it is possible to help human beings live longer than may otherwise have been the case and, thus, responses to death have also changed (Filippo, 2006). With people having become more optimistic and being interested in living longer, a culture of death avoidance and denial has emerged (Marsh, 2009).

Nevertheless, despite the optimism, the inevitability of death creates some degree of anxiety in individuals at some stage in their lives (Niemiec and Schulenberg, 2011: 387). This anxiety may be general and may be borne out of the fear of pain and suffering, the loss of self, the welfare of surviving family members, annihilation or simply the unknown (Neimeyer, Wittkowski and Moser, 2004: 310; Doka, 2009: 291; Niemiec and Schulenberg, 2011: 388). Several studies have been conducted in an effort to measure various forms of death anxiety and to compare variables that do or do not influence such anxiety. The findings from these studies have highlighted the complexity of the subject with researchers acknowledging that it is not yet fully understood (Kastenbaum, 2009; Corr, Corr and Bordere, 2013: 66).

It was initially believed that, the older a person becomes, the more they fear death and, thus, their death anxiety levels increase (Feifel and Branscomb, 1973: 283). With the improvement of instruments for studying death anxiety, it has been found both that older people do not fear death as much as their younger counterparts and also that several factors other than age were found to affect death anxiety (Neimeyer et al., 2004: 320; Benton, Christopher and Walter, 2007: 342; Kastenbaum, 2009; Corr et al., 2013: 56). In a comprehensive review of the relationship between age and death anxiety, it was reported that death anxiety “was heightened for older adults who (a) had more physical health problems, (b) reported a history of psychological distress, (c) had weaker religious beliefs, and (d) had lower ‘ego integrity’, life satisfaction, or resilience” (Fortner, Neimeyer and Neimeyer, 1999: 387). Younger subjects were found to fear such things as “bodily decomposition, pain, helplessness, and isolation, whereas older subjects were more concerned about loss of control and the existence of an afterlife” (Fortner et al., 1999: 390). In addition, women were found to report higher death anxiety as compared to their male counterparts (Lester, Templer and Abdel-Khalek, 2007: 256), people who firmly believe in an afterlife showed less death anxiety (Wink and Scott, 2005: 208), while life accomplishments and past and future regrets were also shown to play a role (Tomer, Eliason and Wong, 2007: 466). Death anxiety has also been examined in terms of other demographic and personality factors which included occupation, health status, experience with death and psychopathology (Tomer and Eliason, 1996: 350). Of particular interest to this study was the finding that medical and non-medical care givers, such as crisis intervention workers, displayed greater apprehension about their own death and dying as compared to their counterparts (Tomer et al., 2007:466). Other studies showed that this tended to result in conservative medical decision making while some physicians were sometimes reluctant to disclose terminal diagnoses and exhibited a generally negative attitude regarding dying (Neimeyer et al., 2004: 323).

Most studies conducted on death attitudes used descriptive cross-sectional methodologies and focused on death anxiety using self-reporting questionnaires. Fear of dying, also known as thanataphobia, refers to a specific and conscious fear of death, which may be functionally debilitating and inhibit personal growth (Niemiec and Schulenberg, 2011: 388). Neimeyer (1994) recommends that it is important to distinguish between fear of dying and death anxiety.

Some alternatives to death anxiety include death denial, death avoidance and death acceptance. Nevertheless, whichever way we perceive death, our attitude towards death and dying may have an impact on both our wellbeing and our definition of personal meaning and may also determine how we live our lives (Neimeyer et al., 2004: 310; Tomer et al., 2007: 466; Wong and Tomer, 2011). Death denial and avoidance are futile as various events in life, such as a terminal illness, an unexpected death of a loved one, or a disaster will force us to confront the stark reality of mortality (Wong and Tomer, 2011). Despite our efforts to suppress and repress death awareness, anxiety about our demise may still manifest itself through worries, stresses, depression and conflicts (Yalom, 2008: 216).

Death acceptance and death anxiety are intimately related (Gesser, Wong and Reker, 1988: 113). There are several theories on the concept of death acceptance. However, the three-component model that was introduced by Wong in 1994 has remained popular in contemporary literature (Neimeyer et al., 2004: 337). This model introduces the concepts of neutral acceptance, approach acceptance and escape acceptance. Neutral acceptance refers to the acceptance of death as an integral part of life and it is neither feared nor welcomed while approach acceptance is linked to the belief in a happy afterlife and is associated with a positive outlook on death. On the other hand, escape acceptance results from living conditions that are “felt unbearable by the individual such that death seems an attractive alternative to life” (Neimeyer et al., 2004: 322). This model is just one viewpoint that serves to broaden the conceptual framework for understanding death attitudes.

Two major implications of death-related attitudes include the fact that such attitudes may vary greatly and that human beings may “reflect on their own and other possible attitudes, select with some degree of freedom the attitudes they wish to hold, and change their attitudes in light of new encounters or additional reflection on matters related to death” and dying (Corr et al., 2013: 60).

2.3.2 Current Theories of Dying

Research over the last fifty years has resulted in multiple theories about death and the dying process (Copp, 1998: 382). As observed by Kastenbaum and Theull (1995), these theories do not fit the scientific meaning of “a coherent set of explicit propositions that have predictive power and are subject to empirical verification” (Kastenbaum and Thuell, 1995: 181). Nevertheless, they do contribute to our understanding of dying, thus helping to inform current practice and care for the dying. Some theories enjoy more popularity within certain disciplines while some contemporary studies offer criticisms, alternatives and modified theories. The next section reviews the stage, phase and task-based theories that continue to inform approaches to dying patients, their families and those who care for them.

2.3.2.1 Five-stage Theory

In a ground-breaking study, Dr Elizabeth Kubler-Ross, a Swiss-American psychiatrist, famously and controversially interviewed more than 200 dying patients in an effort to learn about and document their experiences (Kubler-Ross, 1969). Her study focused on the psychosocial reactions in adults who were dying and led to the development of the five-stage theory of grieving which has since featured as the principle paradigm in the field of coping with dying (Copp, 1998: 382). Denial, anger, bargaining, depression and acceptance are listed as the psychological responses which the dying individual experiences with acceptance as the desired destination to be achieved.

Although this theory remains popular, it has received sharp criticism from both scholars and those who work with dying persons (Corr et al., 2013: 156). There is research that does not support this model and many clinicians who work with the dying have found the model to be inadequate, superficial and misleading (Corr, 2015: 16) The most important criticism of the theory is its mechanistic approach that suggests that the dying person moves through the universal five stages (Copp, 1998: 383) while the physical and spiritual dimensions are excluded (Corr et al., 2013: 154).

The latest editions of popular emergency care provider textbooks, such as the Mosby's Paramedic Textbook (Sanders et al., 2012) and Nancy Caroline's Emergency Care in the Streets (Caroline, 2013) still refer to this model despite there being "no independent confirmation of its validity or reliability" (Corr et al., 2013: 152).

2.3.2.2 Three-stage Theory

In an attempt to redress some of the flaws in Kubler-Ross's theory, Buckman (1993) proposed a three-stage model (Copp, 1998: 383). In terms of this model, a person's character and the way in which the person has coped with difficult situations in the past are said to be consistent with the way in which the person will react when confronted with the threat of impending death (Copp, 1998: 383). The three stages include the following:

- the initial stage ('facing the threat') in which there is a mixture of reactions characteristic of the individual
- the chronic stage ('being ill') during which there is resolution of those elements in the initial response which are resolvable, diminished intensity of emotions and often depression, and

- the final stage (‘acceptance’) when the patient accepts that they are dying. However, this stage is not viewed as essential provided that the patient is not distressed and is communicating normally (Copp, 1998: 383).

Although Buckman’s three-stage theory was viewed as an improvement on the five stage model, it was also criticised for “appearing ‘mechanistic’ at the general or macro-level” and for providing a “unidimensional approach to the multi-faceted process of dying” (Copp, 1998: 384).

2.3.2.3 Awareness Phase Theory

Awareness phase theory was deemed to be relevant to this research study as it relates to the important aspect of communication between healthcare providers and patients around death and dying. In 1965, Glaser and Strauss (1965) analysed the interactions between hospital staff and patients with life-threatening illness using participant observations and interviews (Glaser and Strauss, 1965). They described four contexts of awareness of dying between hospital staff and patients, namely, closed awareness, suspicion awareness, mutual pretence awareness and open awareness (Copp, 1998: 384). With closed awareness the staff members are aware of the patient’s poor prognosis but do not share this information with the patient, with the healthcare providers evading the topic. Inevitably, however, the level of awareness changes to either suspicion awareness or to full awareness of the prognosis. Suspicion awareness, as the name implies, is described as an unstable situation in which the patient begins to suspect the seriousness of their condition and attempts to confirm the suspicion by examining their records or confronting the healthcare provider directly. In such a situation the possibility exists that the patient may either die without knowing the truth or the patient may obtain the confirmation that they sought and then move to full awareness.

This may lead to the ‘mutual pretence’ phase, where both the patient and the healthcare provider know that the patient is dying but choose to pretend that he or she is going to live. Open awareness is when both staff and patient know and choose to acknowledge in their actions that the patient is dying (Copp, 1998: 384). In her review of this theory, Dr Gina Copp (1998) states that “it is fraught with uncertainties and ambiguities giving rise to divergent expectations of ‘appropriate dying’” (Copp, 1998:

385), but acknowledges that it provides useful insight into the behaviours and responses of all of those who face the dying process.

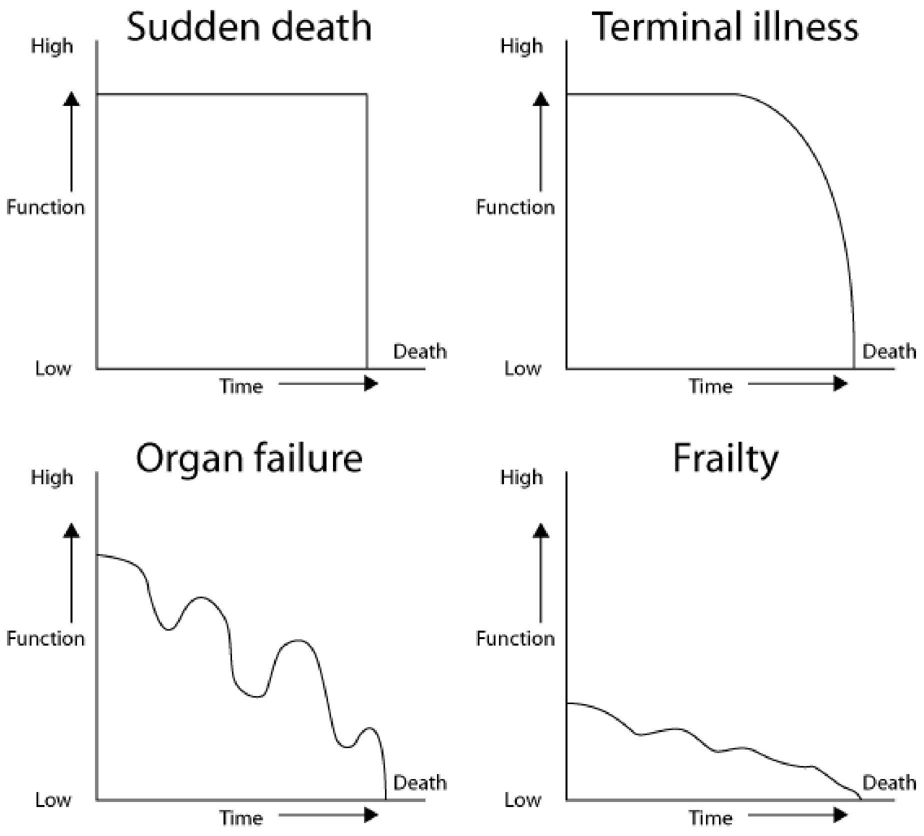

Figure 2.1 Contrasting dying trajectories

Source: Lunney et al., 2003

Glaser and Strauss also noted that different causes of death are typically associated with different patterns of dying which are known as dying trajectories (in Corr et al., 2013). The duration in the dying trajectory refers to the time between the onset of dying and the arrival of death. This concept was further studied using empirical data to measure the trajectories of functional decline (Lunney et al., 2003: 2387).

Figure 2.1 above depicts a highly functioning individual who experiences sudden death as opposed to an individual who is frail and with low functionality and who experiences a slow decline towards death. Terminal illness is characterised by a steady, predictable decline, while other illness may demonstrate a fluctuating pattern between short-term improvements and relapses before finally plunging down to death. The death trajectories illustrate death expectations. Glaser and Strauss noted that “conflicts and tensions in patient, family and medical /nursing staff occur when an expected death trajectory changes … when a patient unexpectedly dies or continues to linger when a swift death is expected" (in Copp, 1998: 385)

2.3.2.4 The Living-Dying Interval/Phase Theory of Dying

Pattison (1977) proposed the living-dying model for understanding the process of dying (Pattison, 1977: 335). According to him, we all project a 'trajectory' for our lives although he argued that this "trajectory is changed when a crisis occurs, such as the knowledge of death" (Copp, 1998: 385). The living-dying interval occurs between the "crisis of the knowledge of death" and the "point of death". Pattison (1977) postulates that it is essential that healthcare providers deal appropriately with the reactions of a patient in the acute crisis phase in order to prevent the patient's life disintegrating into chaos.

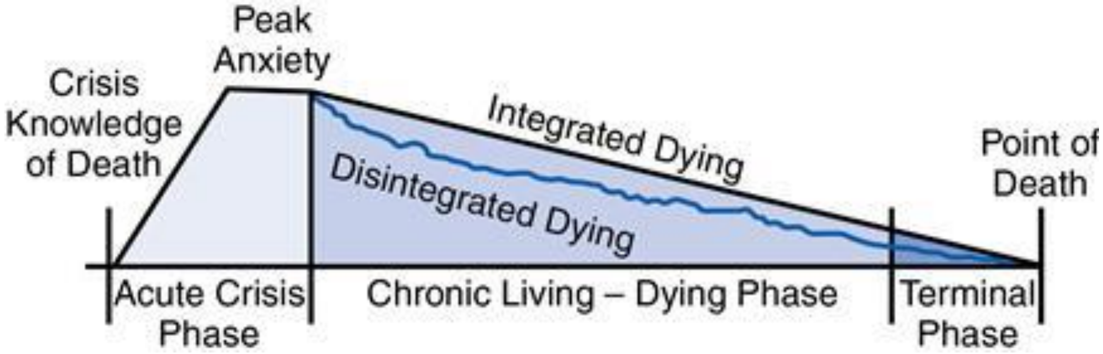

Figure 2.2 Phases of dying

Source: Pattison, 1977

As illustrated in Figure 2.2 above, Pattison (1977) describes the following three clinical phases, namely, the acute crisis phase, chronic living-dying phase and the terminal phase. The task of the healthcare provider is to respond to the different ways in which the person concerned adapts to the chronic phase and then, finally, to enable the person to move into the terminal phase (Pattison, 1977: 335). This clinical model "stems from a combination of psycho-dynamic and humanistic frameworks" (Copp, 1998: 385) and takes into account the pace, feelings and reactions of the patient.

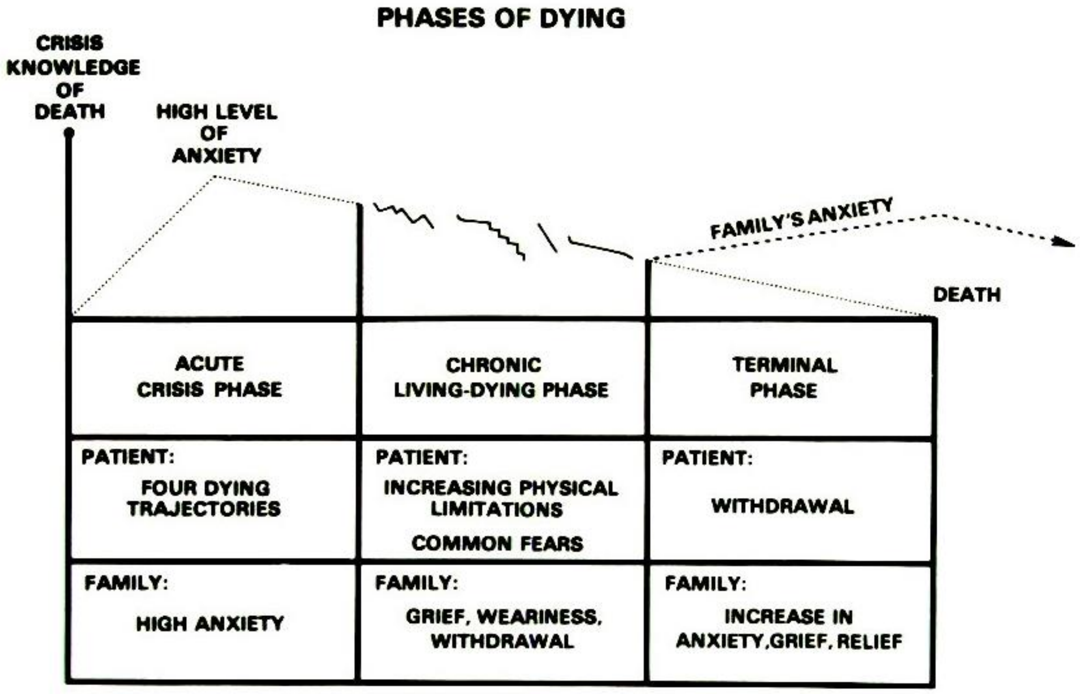

Figure 2.3 Modified living-dying phase

Source: Pattison, 1977

Figure 2.3 above, depicting Pattison's (1977) three phases, integrates the family and the patient into the phases and illustrates the increase in the family's anxiety as the patient enters the terminal phase and after the death, thus highlighting the need for further care beyond the death.

2.3.2.5 The Task-based Theory of Dying

In Pattison's living-dying phase theory he mentions three tasks that the caregivers of dying persons should perform. However, he does not expound on the tasks of the dying person. The subsequent theorist, Kalish (1979), introduced the notion of the tasks of the dying person. Corr (1992) then modified this notion and proposed a task-based approach to coping with dying as a "paradigm for understanding the work of those who are dying and those who care for the dying" (Copp, 1998: 386).

Corr (1992) based his model on the four dimensions in the life of a human being, namely, the physical, the psychological, the social, and the spiritual (Corr, 1992: 82). A key advantage of this approach was that it was not linear as were the previous stage or phase theories while there is an inherent assumption of individuality and autonomy.

Some basic types of tasks in coping with dying are suggested in each of the four dimensions mentioned. "The physical task was to satisfy bodily needs and to minimize physical distress in ways that are consistent with other values” (Meagher and Balk, 2013: 154). This suggestion resonates well with healthcare providers who seek curative treatments although it also poses a unique challenge when applied to dying patients. This idea is explored further later in this chapter.

The psychological task is to maximise the psychological security, autonomy and richness in living (Corr et al., 2013: 158). The major feature of this task is the individual’s ability to remain in charge of their life, although Corr (1992) acknowledges that no one has complete control over all aspects of their lives (Corr, 1992: 81). This acknowledgement of interdependence leads directly to the third area of the task work in coping with dying, namely, the social task. In respect of the social task Corr suggests that sustaining and enhancing interpersonal attachments and interaction with social groups within society or with society itself are valued by the coping person (Corr et al., 2013: 159). The coping person refers not only to the person who is dying and also includes the person’s family, colleagues, friends and peers. This social aspect provides the central underpinning of Corr’s model.

The spiritual area of the task work in coping with dying requires an understanding that “spiritual concerns are not limited to or identified with religious concerns” (Corr et al., 2013: 160). Three common themes of meaningfulness, connectedness and transcendence are identified in an effort to foster hope. In respect of meaningfulness the dying person seeks to find meaning for their suffering and existence while the theme of connectedness explores the disconnection that the person may feel from their body or people and ways in which the person may reconnect. Transcendence goes beyond meaning and connectedness to a higher plane and refers to what happens after the person dies. For the religious there is the hope of life after death while the atheist or agnostic often seek to leave a legacy and to contribute to life through their work, students or descendants (Corr, 2015: 23).

The latest handbook of thanatology, *Handbook of thanatology: The essential body of knowledge for the study of death, dying, and bereavement* (Meagher and Balk, 2013) highlights the fact that Corr’s model is not widely applied although it does represent a possible direction for new approaches to and models of the dying process. Corr (1992) argued that it is “crucial for the theories to contribute to improved understanding, empowerment, participation and guidance for helpers to cope with dying” (Corr, 1992: 93). His task-based theory does, indeed, contribute to this although it is noted by other theorists that it does so on a macro-level and leaves many of the deeper issues unexplored (Kastenbaum and Thuell, 1995: 182).

These theories of dying are not intended to be prescriptive and each one has its own limitations. They do, however, represent the major contributions to the field of dying and define the current state of knowledge (Corr et al., 2013: 164).

2.3.3 Shared Experience of Dying

The experience of dying is not exclusive to the person with the life threatening/limiting condition. It impacts on the people close to the person such as family, friends, colleagues, and people within the person's community and social circles, including healthcare providers and carers. This is usually unchartered territory for most people and the array of reactions, responses and attempts to offer support or help may be shrouded in uncertainty, thus resulting in unhelpful communication, inappropriate or insensitive gestures and a mixture of emotions. These reactions are unpredictable and are influenced by various factors that may be overwhelming for the person who is coping with the realisation of their mortality as well as for those around them. Everyone wants to help but, as Corr states: "there are no magic formulas here" (Corr et al., 2013: 164).

The responsibility of caring for persons who are coping with dying does not only rest with specially trained people (Goldman, 2002: 208; Golubow, 2002: 170; Yoder, 2011: 147). Dame Cicely Saunders, who initiated the modern hospice movement, is reported (Corr et al., 2013: 201) to have said that "dying persons ask three things of those who care for them: (1) 'Help me' (minimise my distress); (2) 'Listen to me' (let me direct things or at least be heard); and (3) 'Don't leave me' (stay with me: give me your presence)". Family and friends are usually ideally positioned to provide much of this care although they themselves also have to cope and deal with dying from their own perspective. They are faced with the prospect of life without their loved one and everything that is associated with that loss. Yoo, Lee and Chang (2008) note that the family are "quasi-patients" and need to be acknowledged and helped to deal with stress or difficult situations more effectively (Fox-Wasylyshyn, El-Masri and Williamson, 2005: 335; Yoo, Lee and Chang, 2008: 225).

The family, helpers and healthcare professionals all share in the experience of dying. This experience encompasses the psychological, physiological, social and spiritual dimensions to varying degrees for each of them. The family's experience is often the most intense due to their relationship with the dying person and the fact that they are usually unprepared and untrained. Several studies have showed that families spent more than 12 hours a day caring for their loved ones and, in doing so, experience a low quality of life, high levels of burden and depression (Andershed, 2006: 1160; Yoo et al., 2008: 226). Although Doka (2009) recommends preparation and training, the reality is that this often does not take place (Doka, 2009: 291). It is vital that healthcare providers and other helpers from outside of the family are aware of the family's needs and offer support to prevent or limit the exhaustion that may arise from the family's overly heroic efforts (Corr et al., 2013: 188).

Self-care and stress management are essential to prevent or minimise some of the harmful and negative aspects that may be experienced (Andershed, 2006: 1163). These include stress, anxiety, compassion fatigue and burnout (Papadatou, 2009: 330).

2.3.4 Caring for the Dying

The term 'dying' is often used only when speaking about terminal illnesses and, in particular, cancer. However, cardiovascular disease has remained the leading cause of dying in recent years, followed by cerebrovascular disease, respiratory disease and cancer (Pagidipati and Gaziano, 2013: 749). Ischaemic heart disease is ranked as the leading cause of global mortality, accounting for 1.4 million deaths in the developed world and 5.7 million deaths in the developing regions (Lopez et al., 2006: 475).

The average life expectancy in industrialised countries increased in the last century and is continuing to increase as medical science continues to find cures and technologies in order to treat ailments in an attempt to extend life (Cassel, 2001: 35; Glannon, 2002: 339; Harris and Holm, 2002: 355; Partridge et al., 2009: 68). Health care providers and health care institutions have focused on curative measures and, as a result, many people are hospitalised and end up dying in hospital, often unaware and unprepared (Corr et al., 2013; Meagher and Balk, 2013). The majority of people consult healthcare professionals in the hope of finding a cure while many healthcare professionals tend to approach disease using a biomedical model that views disease as a specific entity with predictable causes (Meagher and Balk, 2013: 92). Ironically, by 2007, nearly 44% of the deaths in the United States had occurred in hospitals or acute care facilities, while approximately 22% had occurred in long-term care facilities (Kastenbaum, 2009: 544; Corr et al., 2013: 23). By contrast, in developing countries individuals do not have the same access to healthcare institutions and, as a result, the majority die at an earlier age and usually at home under the care of the family and community (Meagher and Balk, 2013: 67).

When individuals become unwell, they rely on healthcare providers for diagnosis and treatment. The exact point at which treatment goals should shift to comfort goals poses both a medical and ethical dilemma for the healthcare provider, the patient and the family. Ideally, the patient should be aware of their prognosis as early as possible to enable the person to contribute in the decision making process about what care the patient wants, where they want to receive such care and whom they would like to be involved in this care (Larson and Tobin, 2000: 1573; Preston and Kelly, 2006: 121). Such conversations may lead to an improved quality of remaining life, as well as to advanced care planning regarding resuscitation and the use of artificial nutrition, hydration and hospitalisation, and should also involve the family members and health care professionals (Dunn, 2001: 80).

There have been significant improvements in the care that is available for the dying. Hospice care, palliative care, long-stay care or nursing home care, outpatient palliative care, home care and end-of-life care are some of the care options that are evolving to address the needs of the dying patient. Some of these terms may sound repetitive and overlapping although in some instances they are refined definitions of care. For example, hospice care and palliative care are usually used interchangeably in the literature although more contemporary literature makes a distinction between the two. We will examine some of these distinctions and similarities below in the attempt to understand the complexity of care that is required by the dying while also exploring the concept of a ‘good death’.

2.3.4.1 Hospice Care

Dame Cicely Saunders is credited with founding the modern hospice movement in 1967 in England when she started St Christopher’s (Stillion, 2006: 11). Hospices have now opened throughout the world and are regarded as the ‘gold standard’ in care near the end of life (Casarett, 2006: 2; Adorno, 2012: 199; Torpy, Burke and Golub, 2012: 200). The term ‘hospice’ is described as a philosophy and not a building or a facility.

In addition, this philosophy may be applied in various locations where the need arises. The hospice philosophy affirms life and adopts an holistic approach to caring for both the patient and the families under the auspices of an interdisciplinary team of specialists providing a continuum of care both before and after death occurs (Corr et al., 2013: 203). This is illustrated in the figure below which is taken from the National Hospice and Palliative Care Organization (NHPCO, 2017).

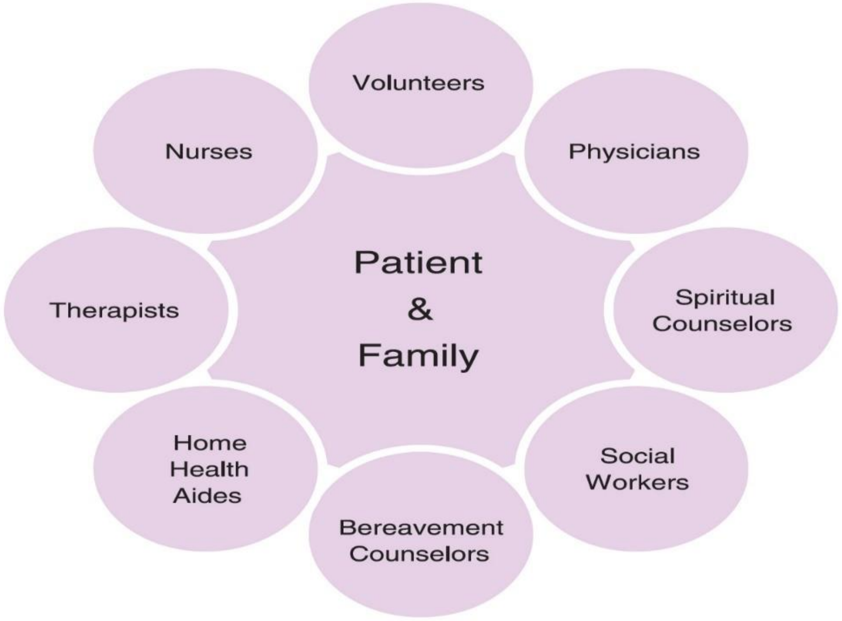

Figure 2.4 Hospice interdisciplinary team

Source: NHPCO, 2017

This interdisciplinary team aims to provide the dying person and their family with “biopsychosociospiritual” care, often in the person’s home (Connor et al., 2007: 238; Leming and Dickinson, 2011: 565). There is a strong focus on alleviating pain and suffering. Several studies have revealed the benefits of hospice and palliative care (Connor et al., 2004, 2007; Casarett, 2006: 3; Leming and Dickinson, 2011: 565; Adorno, 2012: 201).

In order to be eligible to receive hospice care, a person has to be diagnosed with an incurable terminal illness that has a prognosis of six months or less (Meagher and Balk, 2013). This eligibility criterion was established by Medicare in the United States which also determines what Medicare will pay for (Stillion, 2006: 19). A further criterion is that the patient must agree to forego any further attempts at curative treatment (Meagher and Balk, 2013: 39). This may, however, result in some people interpreting a decision to enrol in a hospice programme as giving up and may explain why so many people delay enrolment or completely miss it (Casarett, 2006: 3).

2.3.4.2 Palliative Care

The word 'palliate' in healthcare means to alleviate the symptoms of a disease without curing it (Corr et al., 2013: 223). A significant distinction that has emerged between hospice care and palliative care is that palliative care is applicable early in the course of illness and may be offered in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy (Connor et al., 2004, 2007; Adorno, 2012: 199). The terms palliative care or palliative medicine are now used to designate a type of medical care that addresses the relief of distressing symptoms (Meier et al., 2016: 7).

The American Board of Medical Specialities voted to approve palliative medicine as a subspecialty together with Internal Medicine, Family Medicine, Surgery, Anaesthesiology, Neurology and Emergency Medicine among the specialities that agreed (Meagher and Balk, 2013: 99).

The World Health Organisation defines palliative care as:

> "… 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, psychosocial and spiritual. Palliative care:
>
> - provides relief from pain and other distressing symptoms;
> - affirms life and regards dying as a normal process;
> - intends neither to hasten or postpone death;
> - integrates the psychological and spiritual aspects of patient care;
> - offers a support system to help patients live as actively as possible until death;
> - offers a support system to help the family cope during the patient's illness and in their own bereavement;

- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications" (WHO, 2012)."

2.3.4.3 Institutional Care

There are essentially four institutions that are involved in the care for the dying. These institutions include mainly hospitals of all types, followed by long-term care facilities, home healthcare programmes and hospice programmes (Connor et al., 2004: 316; Torpy et al., 2012: 200) In 2005, in the United States, approximately 75% of people died in an institution, often surrounded by healthcare providers with more than 45% dying in hospitals (Meagher and Balk, 2013: 33). With this high percentage of patients dying in institutions and the establishment of hospice and palliative care principles, there is an expectation that such an institution is the best place in which to receive care and to die.

A major study on dying in institutions was conducted in order to "improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying" (Connors et al., 1995: 1591). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) was published in 1995. This study revealed that people were suffering terrible deaths in hospitals, in pain and with no power to control the last stages of their lives (Connors et al., 1995: 1596). The study was conducted primarily in teaching hospitals and found that pain control was poor, patient's wishes were routinely ignored and advanced directives were often disregarded (Connors et al., 1995: 1598). The study also found that 47% of physicians only were aware of the point at which their patients preferred to avoid CPR, 38% of patients who died spent at least ten days in an intensive care unit and family members reported that their loved ones were in moderate to severe pain for at least half of the time that they were in hospital (Meagher and Balk, 2013:

36; Corr, 2015: 18). As a result of these dismal findings, movements such as ‘the right to die’ movement sprung up, calling for people’s right to avoid such painful and humiliating deaths (Meagher and Balk, 2013: 49). The primary aim of medicine is the provision of healthcare and, thus, the focus is on restoring function. Healthcare providers are slow to admit defeat and resort to hospice care (Preston and Kelly, 2006: 122).

2.3.4.4 End of Life Care

Modern medicine and all of its technical advances make it difficult to decide the point at which it is, indeed, the end of life and when the curative goals must be shifted to caring goals (Bascom and Tolle, 1995: 294; Rutkowski, 2002: 521; Waldrop and Meeker, 2012: 686). An important aspect of end-of-life care is the decision-making process. There is a need for physicians to communicate honestly and openly about a patient’s prognosis to enable the patient to make informed decisions with the help of family members, physicians and hospice and palliative care physicians as early as possible (Preston and Kelly, 2006: 123). To derive the maximum benefit from hospice care programmes, a patient should be enrolled for at least three months. However, the evidence shows that the average stay is 21 days, with a large percentage spending as little as three days in hospice care (Casarett, 2006: 4; Waldrop and Meeker, 2012: 691).

Advanced care planning allows for preferences to be explored prior to the incapacitation of the patient and may include input from both family members and key people in the patient’s life. Issues such as a living will, specifications regarding the administration of life support and the handing over of power of attorney to ensure that there is a trusted person to make decisions when the patient is unable to do so are all important aspects of the end of life period. The timing and manner of a person’s death may be orchestrated or negotiated in some way by the dying person, their loved ones, the healthcare team and, sometimes, the court’s decision on the withholding or withdrawal of treatments (Meagher and Balk, 2013: 219).

2.3.4.5 Dying a ‘Good Death’

The concept of a good death is a dynamic one that continues to evolve, although with little consensus about what constitutes a good death or successful dying (Cottrell and Duggleby, 2016: 686; Meier et al., 2016: 2). Several studies have been conducted in an effort to understand the desires and needs of a dying person and what may be done to fulfil these desires and needs as well as somehow to improve the experience for everyone involved, including the family and the healthcare providers.

Although the notion of a ‘good death’ has been central to the palliative care movement, the evidence, as reported in the SUPPORT study, has documented substantial shortcomings in communication, the overuse of aggressive, cure-oriented treatment, undue pain and a general failure to provide a good death (Connors et al., 1995: 1593). There is, thus, ongoing research to seek ways in which to address these shortfalls and to identify what is required to provide a good death.

The contemporary concept of a good death is “a planned, peaceful, and dignified death, at home, surrounded by family members” (Cottrell and Duggleby, 2016: 686). Cottrell and Duggleby (2016) conducted an integrative literature review of 39 articles on a “good death”, published from 1992 to 2014, and identified the following four main themes: “(1) the good death as control, (2) the wrong good death, (3) the threatened good death, and (4) the denial of dying” (Cottrell and Duggleby, 2016: 686).

The above definition of a good death starts with planning which requires acceptance of dying and the dying process (Zimmermann, 2012: 219). Kellehear (2007) refers to a good death as being a well-managed death (Kellehear, 2007: 297). Such management is influenced primarily by healthcare providers and, thus, the theme of a good death as control has emerged in various ways in the literature, namely, control of the dying activities, control of the timing and place of death, dying as a form of social control, and control of unpleasant physical circumstance (Cottrell and Duggleby, 2016: 687). A death that is not planned or managed is deemed to be a bad death (Seale and Van der Geest, 2004: 883). However, Geoffrey Scarre (2012) states that there is no such thing as a “good” death (Scarre, 2012: 1082). He raised concerns that there is no external criterion for a good death and that it is, above all, dependent on the perspective of the dying individual (Scarre, 2012: 1084).

The control of the dying experience is primarily in the hands of the healthcare providers once the person concerned has subscribed to this notion of a good death. However, this may create a conflict, because the patient’s autonomy is lost in the process (Seale and Van der Geest, 2004: 884; Zimmermann, 2012: 221; Cottrell and Duggleby, 2016: 688). The notion becomes prescriptive with the participants in one study commenting that healthcare providers may imply that “you’re not dying the right way, because you’re not dying the way we think you should” (Steinhauser et al., 2000: 825).

This leads onto the second theme of the ‘wrong good death’ in which it is suggested that the good death ideal may not be representative of what dying people consider to be a good death (Cottrell and Duggleby, 2016: 708). Deborah Carr (2003) raised the question “A good death for whom?” and examined whether the notion benefited the dying individual, the family or the healthcare professional (Carr, 2003: 215). In her study she found that overmedication of patients occurred in some cases in order to reduce the demands on the palliative care staff (Carr, 2003: 218).

In cases where there was an unpredictable dying trajectory, such as with chronic diseases, the healthcare providers and the dying patients may have difficulty knowing when dying actually begins and, thus, the ‘threatened good death’ in which the opportunity to take advantage of end-of-life care is missed (Steinhauser et al., 2000: 825; Carr, 2003: 221; Seale and Van der Geest, 2004: 885; Walters, 2004; Zimmermann, 2012: 221; Cottrell and Duggleby, 2016: 708).

The final theme of ‘denial of dying’ is described in the context of the ideal death being portrayed as a highly planned and tightly controlled event that bypasses the dying process as in euthanasia, physician assisted suicide and the right-to die movement (Clarke, 2006: 154). “The literature reviewed portrays a picture of death and, in particular, the dying process, that is far from good” (Meier et al., 2016: 8).

An Institute of Medicine report (the Institute of Medicine is one of four organisations – National Academy of Sciences, National Academy of Engineering, National Research Council, and IOM – that comprise the National Academies) published 21 years ago described a good death as one that is “free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient’s and family’s wishes, and reasonably consistent with clinical, cultural, and ethical standards” (Field and Cassel, 1997). The patient, family and caregivers are all taken into account in this definition.

Meier et al. (2016) conducted a review of 36 studies published between 1996 and 2015. These studies all provided a definition of a good death and also explored the perspectives of patients, pre-bereaved and bereaved family members and healthcare providers (Meier et al., 2016: 2). They identified the following eleven core themes of good death, namely, “preferences for a specific dying process, pain free status, religiosity/spirituality, emotional well-being, life completion, treatment preferences, dignity, family, quality of life, relationship with healthcare provider, and other” (Meier et al., 2016: 1). ‘Other’ referred to the recognition of culture, physical touch, being with pets and healthcare costs. Each of the themes contained two to four subthemes.

The researchers acknowledged that there were several limitations to their review, for example, there were no common measures of a good death as well as the differences in the research methodologies used by the studies over the years (Meier et al., 2016: 7). They were, however, able to identify a degree of consistency between the three perspectives (patient, family and healthcare provider) in their perception of what a good death constitutes. For all three groups a key component was being pain-free and ensuring patient focused preferences in the dying process (Meier et al., 2016: 5). In view of the fact that the causes of death and dying vary, some of the challenging symptoms, such as difficulty in breathing, may pose more of a challenge than pain management and may, in fact, necessitate changes in the provision of care for the dying (Carr, 2003: 218; Clarke, 2006).

There were also some discrepancies between the respondent groups that were noted in the core themes with life completion, quality of life, dignity and presence of family occurring more frequently in the family perspective than the patient perspective, while religiosity/spirituality was reported more often in the patient perspective (Meier et al., 2016).

Both of these literature reviews (Cottrell and Duggleby, 2016; Meier et al., 2016) highlight the need for more research to examine the concept of the good death from the patient perspective in order to enable the delivery of quality care that is individualised to meet both patient and family needs (Carr, 2003: 220; Cottrell and Duggleby, 2016: 710; Meier et al., 2016: 7). Cottrell and Duggleby (2016) noted that the literature that they reviewed presented an unbalanced and negative view of death and dying with the ‘good death’ being predicated by the absence of negative symptoms and not the presence of positive concepts such as hope, joy and freedom (Cottrell and Duggleby, 2016: 688).

Once death occurs, the healthcare providers and the bereft are left to deal with it. The challenges that arise and preparation to deal with death from the perspectives of both the healthcare providers and the bereft are discussed next.

2.4 DEATH

West's *Encyclopaedia of American law* defines death as the end of life (Lehman and Phelps, 2005). Although this definition is sufficient in most instances, as medicine and science have advanced, the determination of death has become a complex philosophical, legal and ethical issue (Sade, 2011: 147). Defining what constitutes death has implications for grieving, medical treatment, estate planning, organ donation and a host of other legal and ethical issues (Sarbey, 2016: 744).

Physicians are usually required to determine death, make a formal declaration of death and record the time of death. However, this may be difficult at times and a second independent physician may be required to confirm the declaration of death. The fact that the laws and practices surrounding the determination of death are different in various countries has led the World Health Organisation to conduct a technical expert consultation in order to explore this issue and reach universally accepted criteria (Kelly, 2017: 4). Accordingly, it was stated that “the minimum determination of death criteria should be rigorous, global, and acceptable for medical practice worldwide, while remaining respectful of diversities” (Kelly, 2017: 5). This has not yet been achieved and it remains a working document.

Death was traditionally determined by the medical profession using the cardiopulmonary standard which checks for no heartbeat, no breathing and fixed pupils (Sarbey, 2016: 745). In 1954, Joseph Murray successfully performed the first organ transplant when he transplanted a kidney (Hatzinger et al., 2016: 1356). This ushered in a new era in medical science with liver and heart transplants being performed by Thomas Starzl and Christiaan Barnard respectively (Sade, 2011: 148). Organs such as the heart, which are essential for life, had to be transplanted from a person who was dead. This led to the need for a more precise definition of death and, thus, in 1968, an ad hoc committee of Harvard Medical School developed criteria for irreversible coma which was later equated with brain death (Beecher, 1968: 338). These criteria included “unreceptivity and unresponsitivity, no movements or breathing, no reflexes, and a flat electroencephalogram (EEG)” (Sarbey, 2016: 750).

In 1981, the Uniform Determination of Death Act (UDDA) was promulgated. According to the UDDA, “an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards” (Sade, 2011; Sarbey, 2016). This recommendation was accepted by both the American Bar Association and the American Medical Association and was made law in some form in all 50 states in the United States (Madoff, 2010: 191). However, although it was widely accepted in the United States, it remains controversial in some states and, in fact, it has been found that substantial differences in the perceptions and practices of brain death exist in the world (Verheijde, Rady and McGregor, 2009: 411; Jaime Toro, 2015; Wahlster et al., 2015: 1874; Kelly, 2017: 7). Countries with an active organ transplantation programme were more likely to have a brain death provision than those without such a programme (Wahlster et al., 2015: 1877). The Dead Donor Rule (DDR) is a description of the ethical norm that an organ donor must be dead before vital organs are removed (Sade, 2011: 149). The cardiorespiratory model and the total brain model become extremely relevant when considering matters regarding futile treatment, withdrawal of life sustaining treatment (LST) and organ transplantation (Sarbey, 2016: 751).

More recent attempts to determine what constitutes death focus on higher brain functions, what constitutes or defines a person and what it means to be considered to be alive. However, these concepts are not yet scientifically measurable and, thus, they add to the confusion and uncertainty around matters of death, while still being considered extremely relevant and pivotal in difficult cases (Greenberg, 2001; Verheijde et al., 2009: 412; Sade, 2011: 148; Jaime Toro, 2015; Wahlster et al., 2015: 1877; Sarbey, 2016: 751; Kelly, 2017: 8). The UDDA uses the word ‘irreversible’ when it describes cardiorespiratory arrest and the loss of total brain function. However, medical science is continuing to develop ways in which to reverse such states, with CPR, artificial ventilators, artificially supplied fluid and nutrition (AFN) and circulatory support machines, thus rendering the definition less precise and open to interpretation (Sade, 2011: 149). With the shortage of organs for transplant becoming acute over the last 15 years, the Donation after Cardiac Death (DCD) recommendation has faced opposition and the importance of an advanced directive or surrogate decision maker has been highlighted (Greenberg, 2001; Clark, 2006; Verheijde et al., 2009: 413).

The cases of Karen Ann Quinlan and Terri Schiavo are considered to be seminal, ‘right-to-die’ cases that have influenced laws, policies, end of life decisions and the determination of death (Clark, 2006). In both these cases, emergency care providers were involved in the resuscitative efforts that played a pivotal role in the series of events that followed. Quinlan suffered respiratory arrest after ingesting a mix of alcohol and strong sedative medication and was given mouth-to-mouth resuscitation by paramedics en route to the hospital where she was placed on a ventilator (Quinlan, Quinlan and Battelle, 1977; Kinney et al., 1994). Terri Schiavo suffered cardiac arrest due to a suspected electrolyte imbalance which resulted from an eating disorder (Hook and Mueller, 2005). Paramedics performed cardiopulmonary resuscitation (CPR) on her and were able to get her to hospital with a pulse (Hook and Mueller, 2005; Clark, 2006). Quinlan was first in a coma and then in a persistent vegetative state (PVS), dependent upon a respirator and with little hope of recovery (Clark, 2006). Quinlan’s parents won a court case to have their daughter taken off the ventilator after a year. Although it was expected that she would die soon afterwards she lived for a further nine years after the removal of the ventilator (Verheijde et al., 2009: 419). Schiavo’s husband fought to have his wife’s artificial nutrition terminated after she had remained in a PVS for 15 years (Clark, 2006). He eventually won the lengthy case and Terri died in 2005.

Both of these cases highlighted ethical, religious, medical, legal and social issues and, after 30 years, we are still struggling to bridge the gaps in our knowledge, understanding of and preparedness to deal with death and dying (Clark, 2006). Living wills (advance directives) do not protect patient autonomy as they are seldom executed while many people do not know what medical treatment they would want or what choices would be available. Thus, living wills have not been shown to alter patient care at the end of life (Clark, 2006; Verheijde et al., 2009; 421). The list of terms used to describe mentally incompetent patients continues to increase from coma to akinetic mutism (locked-in syndrome), to persistent vegetative state with the gap between medical science, law and ethics continuing to widen and making it extremely difficult for healthcare providers who have to make critical decisions (Greenberg, 2001; Clark, 2006; Jaime Toro, 2015).

2.4.1 Healthcare Providers and Death

In the main healthcare providers who face death and dying as a regular aspect of their work find this a challenging and sometimes stressful aspect of their work (Field and Howells, 1988: 9; Weeks, 1989: 18; Dyer, 1992: 1269; Norton et al., 1992: 236; Hopkinson, Hallett and Luker, 2005: 127). A study conducted among healthcare workers found that “personal views, socio-economic status, beliefs and values, occupational experience, and workplace interventions interact to shape 'worldviews' about death and dying” (Loiselle and Sterling, 2012: 250). The Institute of Medicine reported that, in order to provide optimal care at the end of life, healthcare providers are required to possess strong interpersonal skills, clinical knowledge, technical proficiency that is informed by evidence, values as well as personal and professional experience (Field and Cassel, 1997). Furthermore, culture informs one’s beliefs and values in relation to illness and death, the experience of pain, the ethical imperative for truth telling, and the practices around the care and disposal of the body (Koenig and Gates-Williams, 1995: 245).

Medical science has traditionally focused on alleviating illness and averting death and, thus, the death of a patient is often seen as a failure (Leming and Dickinson, 2011: 565). “This may heighten the difficulty physicians experience with dying patients” (Pessagno, Foote and Aponte, 2014: 211). Doctor Hafferty (1998) describes a process of medical socialisation which consists of an ongoing, tension-ridden series of encounters in which lay values and attitudes are cast aside and replaced by “medical ways of seeing and feeling” (Hafferty, 1998: 404). He states that medical students change from ordinary people into physicians with ‘extraordinary’ abilities to manage issues surrounding health, illness and healing while also mastering the skills of coping with the deaths that they will encounter (Hafferty, 1998: 407). In his somewhat sarcastic description, he highlights the “informal” or “hidden” curriculum in medical education that goes far beyond formal instruction (Pessagno et al., 2014: 221), and which often results in the healthcare providers being left to cope with the stressful aspects of their jobs.

Nurses and physicians who work in the wards, especially those caring for terminally ill patients, may develop interpersonal relationships with the patients and their families and, therefore, have a more personal experience with death and dying as compared to others who are involved (Hopkinson et al., 2005: 128). They may sometimes undergo a psychological ‘hardening’ as a result of their repeated exposure to death (Loiselle and Sterling, 2012: 253). In a study designed to compare and contrast the death attitudes of hospice and hospital-based health care providers, it was found that the hospice employees demonstrated greater ease in caring for dying patients, while the hospital workers displayed higher death anxiety and discomfort in dealing with terminal patients (Carr and Merriman, 1995: 287).

Another study which aimed to compare the levels of death anxiety and coping responses between hospice nurses and accident and emergency (A&E) nurses also obtained a similar result, with the hospice nurses demonstrating lower death anxiety as compared to the emergency nurses (Payne, Dean and Kalus, 1998: 701). The A&E nurses in the study reported that they were unable to discuss problems with their colleagues (Payne et al., 1998: 705). An obvious difference between the two groups is the amount of time and preparation that precedes the death. The hospice nurse spends an average of 15.2 days with a patient in hospital and 69 days when the patient is at home (McNamara, Waddell and Colvin, 1995: 222). In addition, the care goals of the hospice nurse differ substantially to the life-saving goals of the A&E nurse. Compared to the A&E nurse the hospice nurse is more prepared for the patient’s demise and aims to ensure a ‘good death’ for the patient which is defined by an awareness and acceptance of and preparation for death by all those concerned (McNamara et al., 1995: 225).

2.4.2 Emergency Department Death

For those working in the emergency department, the deaths are often unexpected and neither the staff nor family has an opportunity to prepare for such a death (Parrish et al., 1987: e46; Edlich and Kübler-Ross, 1992: 226; Schmidt, Norton and Tolle, 1992: 645; Olsen, Buenefe and Falco, 1998: 761). “A sudden, unexpected death or impending death is a crisis for the patient, family and emergency department staff” (Ordog, 1986: 797).

It was reported that in 2006 an estimated 249 000 deaths had occurred in the emergency departments in the United States of America (Pitts et al., 2006). Regular exposure to death and trauma has the potential to cause death anxiety in emergency nurses (Brady, 2015: 32). Brady (2015) refers to death anxiety as a debilitating psychopathology that must be acknowledged in order to ensure the implementation of strategies to protect staff and improve care (Brady, 2015: 32).

The emergency department is a unique environment in which the types of unexpected deaths may vary substantially. It is also where medical staff members are most likely to encounter the unexpected and untimely death of a child which is regarded as a critical incident stressor (Donnelly and Siebert, 2009: 422).

Emergency physicians have to stabilise the patient’s condition, provide analgesia and relieve discomfort, initiate or withhold resuscitation for patients suffering cardiac arrest or terminal illness while also being sensitive to the psychological needs of the family (Ordog, 1986: 800). The skills required to cope with sudden death include sensitivity and communication skills but which are not taught in the majority of medical institutions and nor are they discussed in journals (Ordog, 1986: 802).

Physicians should, ideally, undergo a pre-emptive period of preparation and self-reflection before they are confronted by the death of a patient (Heiner and Trabulsy, 2011: 296). The death of a patient in the emergency department may have a profound impact on the emergency physician who may be ill prepared for the personal consequences of such a death (Heiner and Trabulsy, 2011: 297). Many physicians are often reluctant to admit such psychological discomfort (Ordog, 1986: 802) and face the risks of burnout and compassion fatigue (Meagher and Balk, 2013: 407).

2.4.3 Burnout, Compassion Fatigue and Vicarious Trauma

Emergency care providers who deal with issues surrounding death do so during some of the most emotionally charged and vulnerable times in people’s lives (Meagher and Balk, 2013: 406). The emergency care provider “needs to be emotionally open and willing to get very close to intense and difficult emotions’ in order to provide support, understanding and empathy” (Meagher and Balk, 2013: 406). However, the risk associated with this is that it becomes possible that the emergency care provider may vicariously experience a patient’s distress, anxiety and even certain physiological manifestations (Rothschild and Rand, 2006: 253). Brain scans have identified what are termed mirror neurons which imply that we are able to react on a neurological level as if an observed experience of another were our own (Meagher and Balk, 2013: 405). The stress that may be experienced by the healthcare professional may be “due to various internal factors, such as previous or current life experiences, personal death experience, too much emotional investment in patients without sufficient replenishment over too long a time, or from feelings of powerlessness and lack of control in the health care system" (Meagher and Balk, 2013: 406).

Dr Maslach defined burnout when she developed the burnout inventory. She defined it as "a state of physical, emotional and mental exhaustion, depersonalisation, and reduced personal accomplishment caused by long-term involvement in emotionally demanding situations" (Maslach, Rutgers and Leiter, 1997). Compassion fatigue, or vicarious traumatisation, is a form of burnout that may be defined as "a pattern of tiredness and emotional depletion from too much caring and too little self-caring" (Figley, 1995: 268).

Self-awareness and self-care play an important role in avoiding burnout and compassion fatigue (Rothschild and Rand, 2006: 253), and require a cognitive and behavioural approach to one's professional and personal life (Meagher and Balk, 2013: 406). Organisational support through the provision of adequate leave time, supervision and continuous professional development and education, as well as limiting work place stressors, will also help to prevent burnout (Renzenbrink, 2011: 203).

2.4.4 Prehospital Emergency Care Providers and Death

Prehospital emergency care providers face incidents such as motor vehicle accidents, murders, suicides, abuse and child and infant deaths as part of their day-to-day duties. However, the majority of studies tend to focus only on disaster and mass casualty situations and the psychological trauma and stress that they cause (Marmar et al., 1996: 98; Fullerton, Ursano and Wang, 2004: 1370; Smith-Cumberland and Feldman, 2005: 184). However, both the day-to-day encounters and the disasters may be traumatic (Clohessy and Ehlers, 1999: 253; Regehr et al., 2002: 508; Van der Ploeg and Kleber, 2003: i40).

In the prehospital setting deaths are usually unexpected and traumatic and occur in unpredictable and uncontrolled environments. The emergency care provider is expected to deal with death, dying and bereavement in a professional manner. This often includes counselling a dying patient, deciding when to withhold, start or stop resuscitative efforts, delivering death notifications and consoling the bereaved. Although some emergency medical services provide clinical practice guidelines (CPG)

(Power et al., 2017) to guide the emergency care provider through some of the death-related tasks, the fact that these are seldom taught and assessed may contribute to noncompliance with the guidelines (Smith and Walz, 1995: 258).

A study was conducted using the theoretical framework of emotional and cognitive empathy in order to better understand the factors that lead to high levels of distress among emergency care providers (Regehr et al., 2002: 510). All 86 of the emergency care providers who participated in this study reported that they had been exposed to situations that could be defined as critical events. Any “incident that is sufficiently disturbing to overwhelm or threaten to overwhelm the individual’s usual method of coping” is referred to as a critical incident (Alexander and Klein, 2001: 76). The coping mechanism most frequently described by the emergency care providers involved the deliberate use of cognitive strategies (Regehr et al., 2002: 511). The study found that, as compared to other critical events, the death of a child or a colleague caused the most emotional distress to emergency care providers and that it is often the less sensational events that trigger more intense emotional responses (Regehr et al., 2002: 509).

The Centre for Disease Control and Prevention reported in 2013 that, as compared to before, fewer people were dying in hospitals, and more people were choosing to die at home (Pagidipati and Gaziano, 2013: 751). This means that prehospital emergency care providers will have an increased exposure to dying patients.

There are approximately 295 000 cases of out-of-hospital cardiac arrests (OHCA) every year in the United States with about 177 000 of those being treated by emergency medical services (EMS) (Lloyd-Jones et al., 2010: e46). Despite ongoing efforts to improve the incidence of the return of spontaneous circulation (ROSC) approximately 10% only of OHCA victims survive to the point of hospital discharge (Sasson et al., 2010: 65). At the beginning of this century, the majority of cardiac arrests were transported to hospital so that physicians could perform the declaration and notification of death (Cummins and Hazinski, 2000: 1371). However, a large number of patients are now declared dead by emergency care providers in the prehospital setting (Lloyd-Jones et al., 2010: e48).

This exposure to critical events involving suffering and tragedy may result in emergency care providers experiencing posttraumatic stress symptoms and depression (Regehr, 2005: 509). Although the support of family is a primary mediator of such reactions the family members themselves may be vulnerable to transmitted stress and distress (Regehr et al., 2005: 512). Some of the issues identified in the study include managing everyday job stress, safety fears, and dealing with emotional reactivity and emotional withdrawal on the part of family members after trauma exposure (Regehr, 2005: 512). Unfortunately it would appear that, in the main, the organisational support systems that have been developed for emergency workers neglect family members (Regehr, 2005: 513).

There are several factors that may contribute to the preparedness of emergency care providers to deal with death, dying and bereavement in the prehospital setting. Although their exposure to work related death and dying is unavoidable, a combination of personal, educational and professional factors may contribute to their being able to deal safely, sensitively and efficiently with death, dying and bereavement. Figure 2.5 below attempts to illustrate that death education, death attitude and the personal variables of the emergency care provider may be linked to preparedness. Death education can lead to increased cognitive and emotional competence which in turn may reduce death anxiety and aid with coping. This is illustrated in Figure 2.5 below.

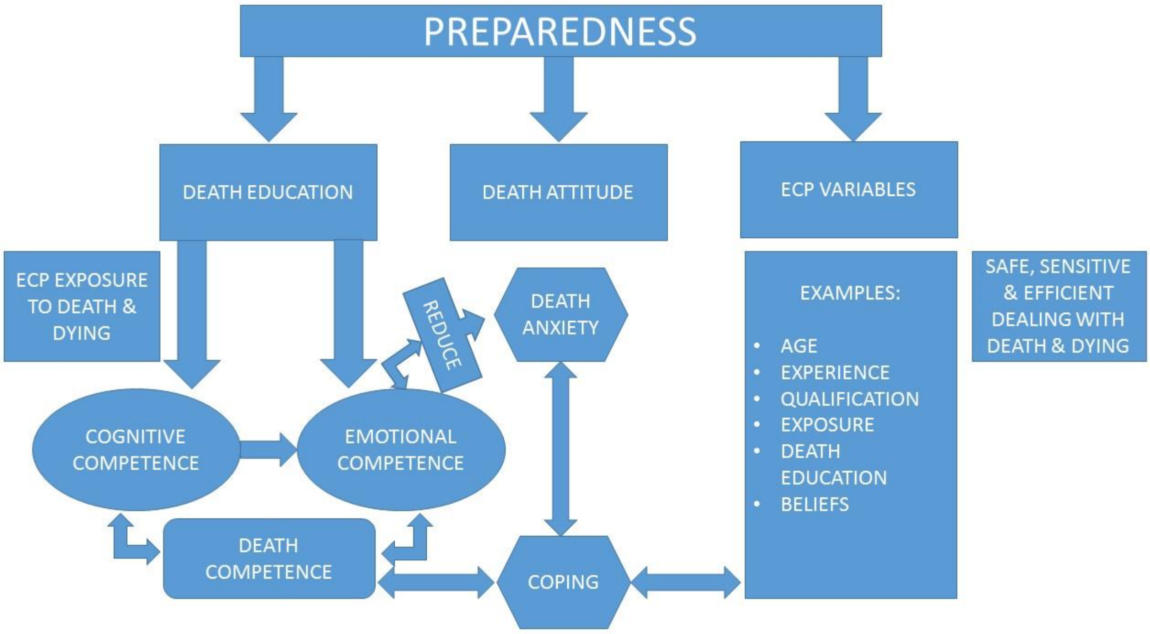

Figure 2.5 Factors contributing to preparedness of ECP to deal with death and dying

The American Heart Association (AHA) is recommending the prehospital termination of resuscitation (TOR) and encouraging decisions to withhold futile resuscitative efforts (Kleinman et al., 2018: e10). Although TOR has been found to be both acceptable and ethically sound (Schneiderman, Jecker and Jonsen, 1990: 949; Marco et al., 1997: 899), many prehospital emergency care providers are reluctant to comply with these guidelines (Ponce et al., 2010: 537). Despite evidence that TOR has been shown to have beneficial effects on family members (Feder et al., 2006: 634), emergency care providers report being uncomfortable with the family members' negative reactions to failed resuscitation (Ponce et al., 2010: 539).

Both the American Heart Association and the International Liaison Committee on Resuscitation (ILCOR) have recommended that family be allowed to be present during cardiopulmonary resuscitation (CPR) (American Heart Association., 2015; Kleinman et al., 2018: e 13). Family-witnessed resuscitation (FWR) has been debated around the world for almost 25 years but its implementation as a standard of care remains controversial (Halm, 2005: 494). Current evidence indicates that the majority of families want to be present and they want to be kept informed about what is going on during a resuscitation (Halm, 2005: 495; Critchell and Marik, 2007: 311; Sak-Dankosky et al., 2014). However, some healthcare providers have expressed concerns that the resuscitation may be disrupted and that families may suffer from adverse psychological trauma (Halm, 2005: 496; Critchell and Marik, 2007: 311; Kianmehr et al., 2010: 4; Monks and Flynn, 2014; Sak-Dankosky et al., 2014; Bashayreh et al., 2015). However, these concerns have not been substantiated with most of the latest research showing that these opinion-based beliefs may be modified with FWR education which would enhance family-centred care (Feagan and Fisher, 2011: 232). One study based in the Muslim setting of four Iranian teaching hospitals found that the majority of CPR responders did not favour the presence of family during cardiopulmonary resuscitation (Kianmehr et al., 2010: 5). Another descriptive quantitative study conducted with the aim of identifying the attitudes and experiences of Jordanian nurses in relation to the presence of family members during the CPR of adult patients found that more than 90% of the participants did not have any experience of or protocol for FWR. Accordingly, the study concluded that education on FWR should be provided (Hayajneh, 2013).

Studies have shown that, in general, prehospital emergency care providers do not receive adequate training on performing death notification and dealing with the bereft (Smith-Cumberland and Feldman, 2005, 2006; Smith-Cumberland, 2006: 638 Douglas et al., 2013a: 152). This may constitute a barrier to the adoption of the American Heart Association guidelines for the termination of resuscitation in the prehospital setting as well as the implementation of FWR as a standard of care (Ponce et al., 2010: 541).

Several studies have shown that emergency care providers are ill-prepared to communicate difficult news (Norton et al., 1992: 235; Smith and Walz, 1995: 257; Smith-Cumberland and Feldman, 2006: 90; Stone et al., 2009: 529; Ponce et al., 2010: 537; Nordby and Nøhr, 2011: 226; Douglas et al., 2013b: 152). Declaration of death and communication with family during resuscitation requires training and may be extremely stressful for the emergency care provider.

An exploratory study conducted in Norway’s National Ambulance Service found that emergency care providers also found it difficult to find the “right words” to communicate with patients on the verge of death, especially during “quiet transports” where there is not much to be done (Nordby and Nøhr, 2011: 226). The researchers in this study highlighted the need for emergency care providers to receive education and training in preparation for both the emotional work they perform and challenging patient communication (Nordby and Nøhr, 2011: 215).

Prehospital emergency care providers also represent a key element in the organ donation process (Akgün et al., 2003: 1273). They may be required to be on the alert for potential organ donors, provide temporary organ preservation (TOP), communicate with family members and activate the transplant coordination team. Prehospital emergency care providers are often required to carry out these aspects of the job, without much preparation or consideration of their personal beliefs with regard to organ donation. A cross-sectional study conducted to assess the knowledge and personal views of healthcare professionals with regard to organ transplants found that there was a lack of knowledge, which had a negative impact on people's attitudes toward organ donation (Akgün et al., 2003: 1274). The process of organ procurement is highly stressful and personal feelings of distress and negative attitudes to the issue of organ donation may be transmitted to others and undermine organ procurement efforts (Regehr et al., 2004: 430).

Emotional labour in this context refers to the need for emergency care providers to remain professional as they encounter difficult situations. It is essential that they regulate their emotions during their interactions with a patient, the patient's family members and the general public. They must remain positive in the face of death and show empathy, while also retaining emotional barriers in order to protect themselves against compassion fatigue (Vettor and Kosinki, 2000: 216).

The complexities associated with determining death as well as the declaration and notification of death described earlier form an integral aspect of the day to day duties of the emergency care provider with the added challenges associated with the prehospital environment (Beaton et al., 1998: 821). Emergency care providers who suffer from death anxiety, also known as thanatophobia, may find it particularly challenging to deal with death, dying and bereavement (Brady, 2015: 32).

Once death has occurred, the healthcare provider must then meet the initial needs of the bereaved friends and relatives (Purves and Edwards, 2005: 28).

2.5 EMERGENCY CARE PROVIDERS AND BEREAVEMENT

Prehospital emergency care providers are in a unique position to influence the grieving process (Smith and Walz, 1995: 63). The grief that occurs after a suicide, murder or unexpected violent or accidental death may differ from normal grief (Roos, 2002: 269). Terms such as catastrophic grief, traumatic grief and chronic sorrow have been used to describe a natural grief reaction that is not final and continues to be present in the life of the griever (Adamowski et al., 1993: 1445; Marmar et al., 1999: 20; Roos, 2002: 269; Wong and Tomer, 2011).

Many of the deaths that are encountered in the prehospital setting are both sudden and unexpected. As a result, the family and friends of the deceased are unprepared and in urgent need of support (Schneiderman et al., 1990: 949; Ponce et al., 2010: 539; Zavotsky et al., 2014).

“Whole groups of devastated patients fall through emergency medicine's safety net without our realizing that they need our help. These are the survivors after sudden unexpected deaths; it is time we stopped ignoring them” (Iserson, 2000: 75). The evidence suggests that the way in which death notifications are conducted may seriously affect the way in which loved ones will cope and grieve (Iserson, 2000: 75). Although much of this research in this context has been conducted in emergency departments, it does, nevertheless, also apply to the prehospital setting and should, therefore, be acknowledged (Purves and Edwards, 2005: 29). It would appear that education, training and, ultimately, preparation for the task of notifying the family that their loved one has died and then dealing appropriately with their reactions is severely lacking for emergency physicians, nurses and, in particular, for prehospital emergency care providers (Iserson, 2000: 76; Smith-Cumberland, 2006: 642; Smith-Cumberland and Feldman, 2006: 91; Ponce et al., 2010: 542; Douglas et al., 2013b: 154).

Although the death notification may cause a great deal of anxiety for the emergency care provider, for the recipient of the news it will “probably be one of the defining moments of their lives” (Haughey, 2000: 68). Emergency care providers do not know whether the death notification will elicit an hysterical or violent reaction, how much emotion they may show, how much they should say and whether they will be able to answer questions about autopsies, organ donation, funeral arrangements and the myriad of issues that may follow their notification (Iserson, 2000: 76). However, many of these fears may be overcome through education and the use of tools or protocols that have been developed (Iserson, 2000: 75). Specific knowledge, skills and protocols may be helpful in assisting the emergency care provider to deal with the bereft (Smith and Walz, 1995: 266 ; Iserson, 2000: 77; Ponce et al., 2010: 542; Roe, 2012: 130; Brady, 2015: 35).

Emergency care providers who have been trained in how to manage family-witnessed resuscitation and death notification may decrease trauma and enhance the ability of family members to cope with the loss of a loved one (Critchell and Marik, 2007; Smith, Walz and Smith, 2009; Hobgood et al., 2013: 501).

2.6 DEATH EDUCATION

Less than a fifth of students in the health professions are offered a full course on death, while the rest are typically provided with death-related content in a few lectures (Wass, 2004: 297). Although the need to include instruction on death and dying in medical education curricula has been well established (Barton, 1972: 169), healthcare education has been slow to design and implement such courses (Smith and Walz, 1995: 257; Smith et al., 2009). This means that healthcare graduates are entering their professions inadequately prepared to care for dying people and their families or to counsel bereaved or suicidal people (Wass, 2004: 293).

Contemporary studies of death, dying and bereavement are remarkable in both scope and range and, yet, this knowledge has not had a significant impact on the curricula of healthcare professions (Wass, 2004: 293) with the majority of courses and programmes focusing on the transmission of knowledge with little attention to helping individuals to address their own anxieties and develop empathy. The methods used to teach death education across healthcare curricula have been found to be either absent or ineffective (Jacques et al., 2011: 121).

Commonly prescribed textbooks used for emergency care training such as Nancy Caroline's Emergency Care in the Streets and Mosby's Paramedic Textbook, have fewer than two pages dedicated to the topic of death and dying and, typically, cover the stages of grief only (Wass, 2004: 295; Sanders et al., 2012; Caroline, Caroline and American Academy of Orthopaedic Surgeons, 2013). However, knowing the stages of grief may not be effective for emergency care providers as they do not witness the later stages of grief such as acceptance (Smith-Cumberland and Feldman, 2006: 89). Formal education should be implemented to reduce the stress that emergency care providers may experience when communicating death notifications. This will also benefit the bereaved (Douglas et al., 2013b: 156).

There is clearly a lack of foundational instruction in death education and a paucity of effective educational resources in this regard (Smith and Walz, 1995: 260; Smith-Cumberland and Feldman, 2006: 89).

In a study which was conducted in the United States, Smith and Walz (1995) reported that nearly all the paramedic programmes offered death education as an integrated part of their curriculum, with a fraction offering it as a separate course (Smith and Walz, 1995: 267).

It is essential that death education courses for emergency care providers differ from those offered to other healthcare professionals while they should "encompass the diversity of the different types of death, yet focus specifically on the differences between hospital and prehospital death" (Smith-Cumberland and Feldman, 2006: 90).

Emergency Death Education and Crisis Training (EDECT) is a 16-hour seminar which includes a lecture, discussions, small group exercises, and role playing (Smith-Cumberland and Feldman, 2006: 90). The course was designed to change the death-related attitudes and behaviours of emergency care providers. It was, in fact, shown to do so in an evaluation study (Smith-Cumberland and Feldman, 2006: 95).

A shorter, two-hour lecture on the death notification procedure was also designed as a Continuing Medical Education (CME) session. It was found to be effective in changing the behavioural intentions of emergency care providers (Smith-Cumberland and Feldman, 2006: 95).

Both courses aim to decrease the trauma suffered by the bereaved. However, specialised training such as Critical Incident Stress Debriefing (CISD) is designed to mitigate the effects of traumatic stress on emergency care providers (Smith et al., 1999: 41).

Emergency care providers are accustomed to learning practical skills, utilising mnemonics and using simulations in their education. Mnemonic based strategies such as GRIEV_ING, SEGUE and SPIKES provide a planned structure for communication and interpersonal relations in the context of death notification and terminal illness (Baile et al., 2000: 101; Makoul, 2001: 25; Hobgood et al., 2005: 502).

Simulation experiences have started to replace traditional models for teaching the skills required to effectively and empathically deliver bad news in medical education (Jacques et al., 2011: 124). An inter-professional death notification simulation was developed and implemented with nurses and social workers. The results were found to be positive with participants reporting increased confidence, decreased anxiety, and increased awareness of the resources required in the death notification process (Galbraith et al., 2014: e95). Undergraduate nursing students in Northern Ireland were introduced to simulation using high fidelity patient simulators in order to develop confidence and proficiency without compromising patient safety (Traynor et al., 2010: 1423). The students reported that simulations were a valuable experience which highlighted gaps in their knowledge, but also improved their confidence levels for future clinical practice (Traynor et al., 2010: 1426).

The goal of death education is to reduce the stress suffered by both newly bereaved persons and emergency care providers and it should, thus, result in death competence. Death competence is, however, a complex task and a multidimensional approach to death education is therefore required.

2.7 DEATH COMPETENCE

The Association for Death Education and Counselling (ADEC) has an established code of ethics (Balk et al., 2007). The concept of death competence is reflected in this code, with the ethical principles of beneficence and non-maleficence being an integral component of the code (Meagher and Balk, 2013: 443).

Both of these principles are familiar to healthcare professionals who seek to help patients and do no further harm. The implication is, thus, that it is unethical to be unprepared to deal with death and dying and that standards should exist to ensure competence on the part of healthcare workers (Doka, 2003: 51).

Gamino and Ritter (2009) coined the term “death competence” to describe the specialised skill involved in tolerating and managing problems related to dying, death and bereavement (Gamino and Ritter, 2009: 419). They illustrate this in a hierarchical model (Fig 2.6) of which cognitive competence and emotional competence constitute essential components that are required to ”support a more developed and refined level of death competence” (Gamino and Ritter, 2009: 421).

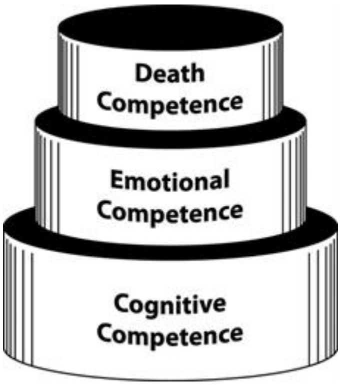

Figure 2.6 Hierarchical model of death competence (Gamino and Ritter, 2009)

Cognitive or intellectual competence refers to a consolidation of sound academic training that will result in proficiency and a set of skills that may be used (Roos, 2002: 269; Gamino and Ritter, 2009: 422; Pope and Vasquez, 2010: 498). Emotional competence, on the other hand, requires psychological resilience, adequate strategies for ongoing self-care, support and the ability to manage one’s own death-related feelings when dealing with death and dying (Roos, 2002: 269; Gamino and Ritter, 2009: 423; Pope and Vasquez, 2010: 498).

Gamino and Ritter's hierarchical model of death competence echoes the sentiments of Herman Feifel (1990) to the effect that dealing with death and dying constitutes both science and humanity and, as such, it is essential that both of these are factored into the establishment of death competence (Feifel, 1990: 541).

There is little evidence and research to suggest that emergency care providers are equipped with the basic competencies to deal with death, dying and bereavement. In fact, the evidence suggests the opposite (Dickinson, Sumner and Frederick, 1992: 281; Smith and Walz, 1995: 267; Wass, 2004: 293; Douglas et al., 2013b: 154).

2.8 COPING STRATEGIES

Emergency care providers experience a high exposure to death, dying and bereavement which may result in their experiencing death anxiety (Brady, 2015: 32). Death anxiety is just one aspect of the complex range of responses that people may experience when dealing with death, dying and bereavement. However, the psychological distress and the stress that may emanate from these situations may be either mitigated or eliminated through the use of certain coping strategies (Fleishman, 1984: 229). Less experience and a lower level of emergency medical technician (EMT) training correlate with increased difficulty in coping with patient death (Norton et al., 1992: 240).

There have been at least three classifications of coping, namely, problem-focused, emotion-focused and meaning-focused (Folkman et al., 1986: 576; Folkman and Moskowitz, 2004: 746). Personality has been shown to influence a person's coping mechanisms (Costa and McCrae, 1992: 655).

Individuals with a controlling personality will usually use problem-focused coping strategies in an attempt to do something constructive and to take action to remove the stressor (Fleishman, 1984: 229; Carver, Scheier and Weintraub, 1989: 267; Minnie, Goodman and Wallis, 2015: 15). On the other hand, people with denial as a personality characteristic tend to use the emotion-focused approach in order to reduce psychological distress. They may reinterpret the situation as a more positive one than initially thought (Fleishman, 1984: 229; Carver et al., 1989: 283).

"Meaning-focused coping is, in its essence, appraisal-based coping in which the person draws on his or her beliefs (e.g., religious, spiritual, or beliefs about justice), values (e.g., 'mattering'), and existential goals (e.g., purpose in life or guiding principles) to motivate and sustain coping and well-being during a difficult time" (Folkman, 2008: 6). This method spans the various personality types and may serve to suppress the debilitating influence that pain and emotional suffering may have on an individual (Gruszczyńska and Knoll, 2015: 2878).

"Education, desensitisation, humour, language alteration, scientific fragmentation, escapes into work and rationalisation" (Palmer, 1983: 162) are some of the strategies used by emergency care providers. Alexander and Klein (2001) add thinking about the positive aspects of the job, concealing feelings and avoidance to this list (Alexander and Klein, 2001: 78).

The coping strategies used by emergency care providers may constitute important risk factors in relation to work-related stress, for example alcohol abuse and blocking out the stressful event (Moran, 1998). It has also been found that peri-traumatic dissociation is indicative of future problems (Weiss et al., 1995: 361).

Emergency care providers tend to demonstrate various coping styles and will not all be affected by events to the same degree (Moran, 1998). Individual differences in reactions to traumatic stress are accepted and taken into account when managing training and in-service education (Moran, 1998).

Coping strategies do not always yield a positive outcome while certain strategies are associated with poor mental outcomes (Aldwin and Revenson, 1987: 338; Folkman and Moskowitz, 2004: 751). It is therefore important that the relevant organisations and educational institutions take cognisance of the risks associated with emergency medical care and that steps be taken to mitigate these risks for new and experienced emergency care providers.

2.9 CONCLUSION

Although the body of knowledge on death, dying and bereavement is continuing to grow, much of it resides in journals and literature consulted by professionals in thanatology which has little impact on the healthcare curricula. It is thus of little benefit to healthcare professionals, least of all those working in prehospital emergency care (Regehr et al., 2002: 513; Wass, 2004: 296; Smith-Cumberland and Feldman, 2006: 95; Ponce et al., 2010: 542; Douglas et al., 2013b: 159).

There is a pattern of resistance and a failure to acknowledge the need for specialised preparation to deal with death, dying and bereavement (Wass, 2004: 289). This study sought to contribute to the existing body of evidence and knowledge in the much neglected area of emergency care education and preparation. It is hoped that this may potentially lead to the development of strategies to expand and improve the measures taken to prepare emergency care providers to deal with death, dying and bereavement.

The next chapter describes and briefly discusses the research methodology that was used to collect, analyse and synthesise the data used in the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

Research has been described as the “systematic and rigorous process of enquiry which aims to describe phenomena and to develop and test exploratory concepts and theories” (Bowling, 2009: 1). This chapter discusses the research design used in the study and includes a description of the study setting, the population, the techniques used to collect and analyse the requisite data, inclusion and exclusion criteria, pilot testing of the research tool as well as the ethical considerations which were taken into account during the study.

3.2 RESEARCH DESIGN

This research study was a descriptive, prospective study situated in the positivist paradigm. A survey method was used to collect quantitative data.

3.3 STUDY SETTING

The United Arab Emirates (UAE) is a constitutional federation comprising seven emirates, namely, Abu Dhabi, Dubai, Sharjah, Ras Al Khaimah, Ajman, Umm Al Quwain and Fujairah. According to recently published figures it has an estimated population of 10 287 089.

Geographically, the UAE spans 83 600 sq. km. and is, thus, slightly bigger than Scotland. The capital, Abu Dhabi, accounts for 87% of the country's total landmass, although Dubai is the largest city with a resident population of 2 407 352. The active, daytime population, which comprises residents as well as tourists, sailors and other temporary residents, is 3 408 000.

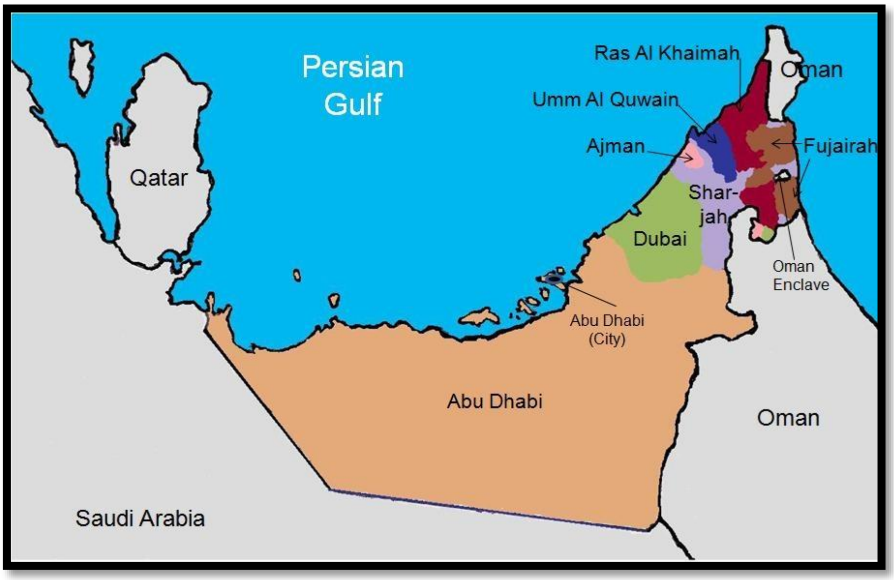

Figure 3.1 Map of the United Arab Emirates

The ambulance services in the UAE are run by two major organisations – the Dubai Corporation of Ambulance Services (DCAS) and the National Ambulance Company (NAC). Historically, the police department in each emirate was responsible for the provision of ambulance services. However, the leadership in Dubai decided to form a separate organisation with the dual function of providing ambulance services and operating as a licensing and accrediting body within Dubai. The Abu Dhabi Police oversees the operations of NAC which provides EMS coverage to the six other emirates.

Smaller private services do operate within the UAE, but they are linked to hospitals and clinics and do not respond to primary call outs.

3.3.1 Dubai Corporation of Ambulance Services

Dubai Corporation of Ambulance Services (DCAS) has 210 ambulances operating out of 76 stations.

The average case load per month is 11 500, with 120 400 calls recorded by the end of the last quarter of the year. A total of 935 cases involving death were recorded in Dubai in 2017 with 896 (93%) dead on arrival and not transported, 43 (4.6%) dead on arrival and transported and 22 (2.4%) who either died at the scene or en route to hospital (Fig 3.2)

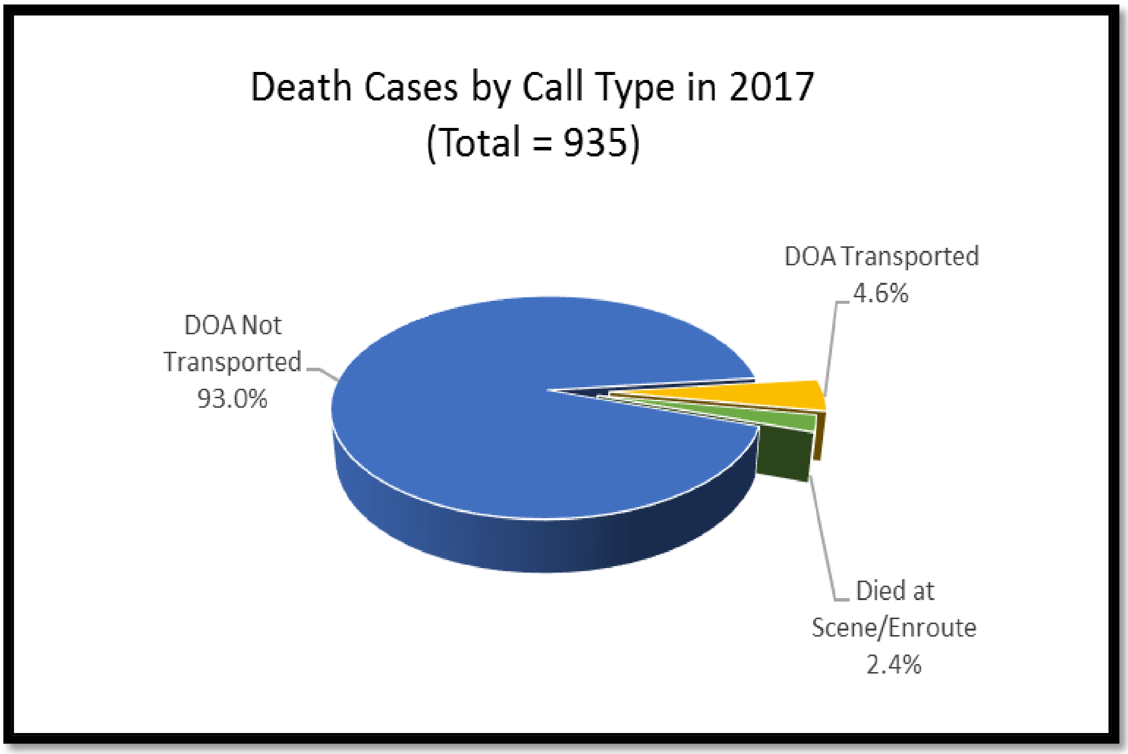

Figure 3.2 DCAS death cases in 2017 (DCAS Strategy and Corporate Excellence Office)

Of these cases, 848 (90.8%) deaths were related to medical conditions while road traffic accidents contributed to 86 (9.2%) of the deaths (Fig 3.3).

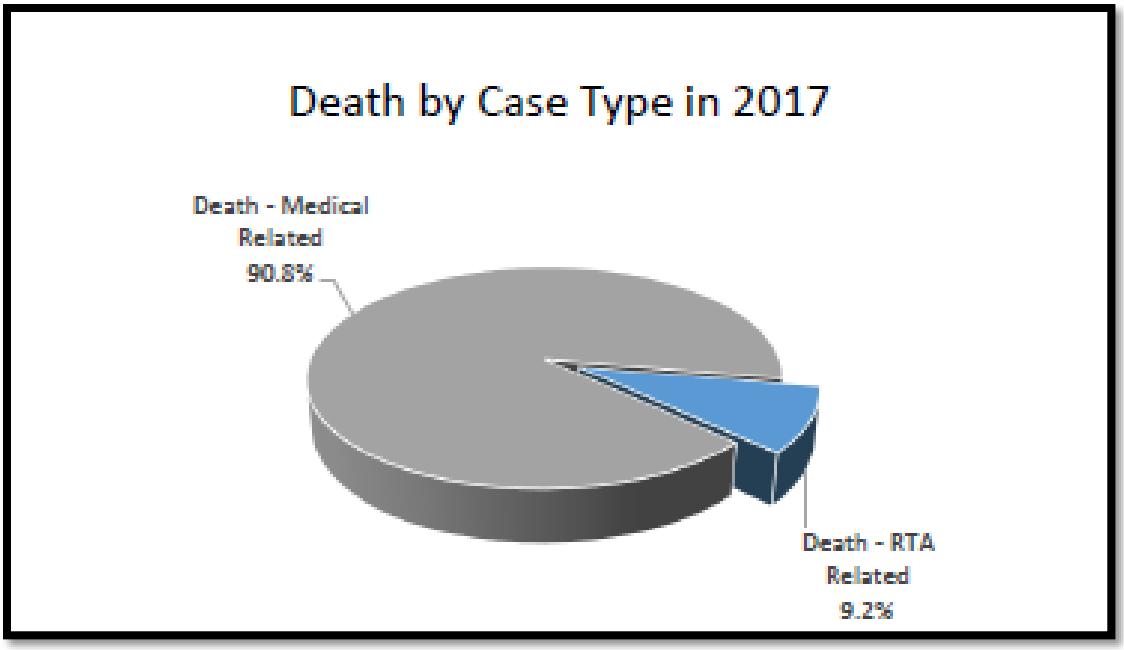

Figure 3.3 Death by case in 2017 (DCAS Strategy and Corporate Excellence Office)

The DCAS administration offices are operational from 7h30 – 3h30, while the ambulance service operates for a full 24 hours. The DCAS is the only service authorised to respond to primary calls. Emergency care providers work on a 12-hour shift system from 5 a.m. to 5 p.m. The shift cycle is two dayshifts, two nightshifts and four days off. There are 76 stations situated throughout the emirate.

Dubai has been divided into six zones, as illustrated below, to distribute the ambulance stations across the emirate to facilitate improved response times.

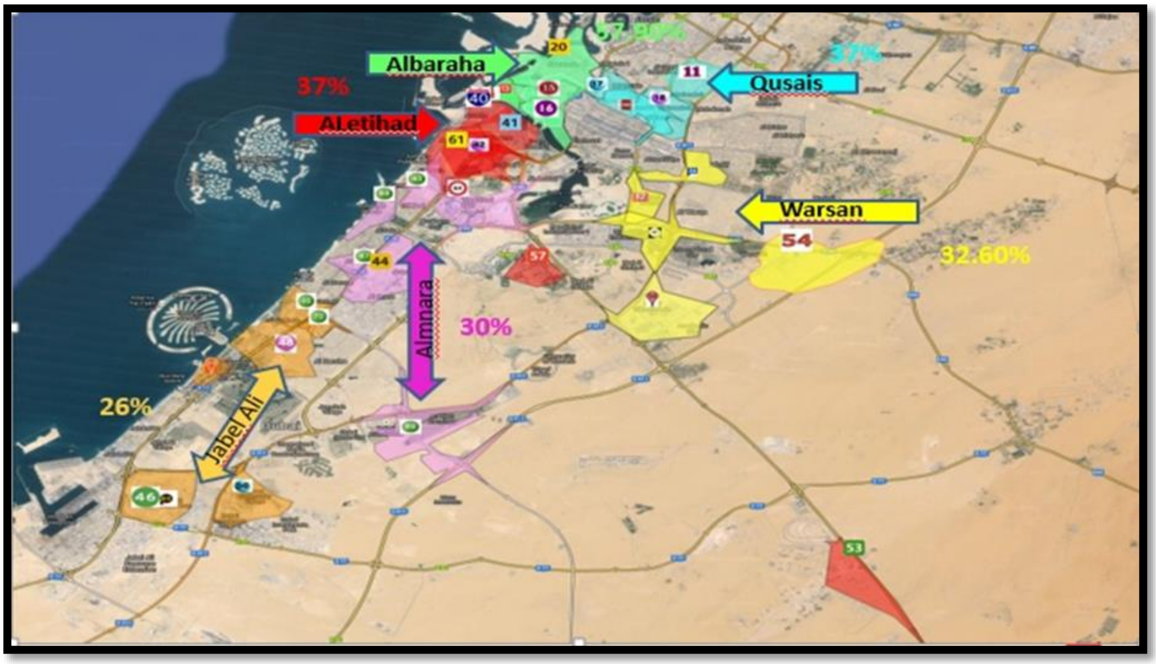

Figure 3.4 DCAS Zonal Division of Dubai (DCAS Strategy and Corporate Excellence Office)

The DCAS has various specialised units which are used to transport patients. These include:

- Medical Intensive Care Ambulance (MICA)
- Paediatric Ambulance
- Mama Ambulance – Female crew who attends to obstetric, gynaecological and female emergencies
- Disaster Response Team
- Bariatric Ambulance
- First Responder Unit

- Doctor Response Unit
- Helicopter Emergency Medical Services
- Desert Response
- Marine Response
- Standard Response Ambulance

These ambulances are colour coded, with awareness campaigns being conducted to enable the community to be able to identify the various ambulances.

3.4 TARGET POPULATION

At the time of the study the staff complement comprised 823 emergency care providers who were mainly expatriates. At the time when they are recruited they undergo an integration process to align their training with the local authority regulations and clinical practice guidelines. The graph below shows the distribution of the nationalities and their qualifications and levels of training.

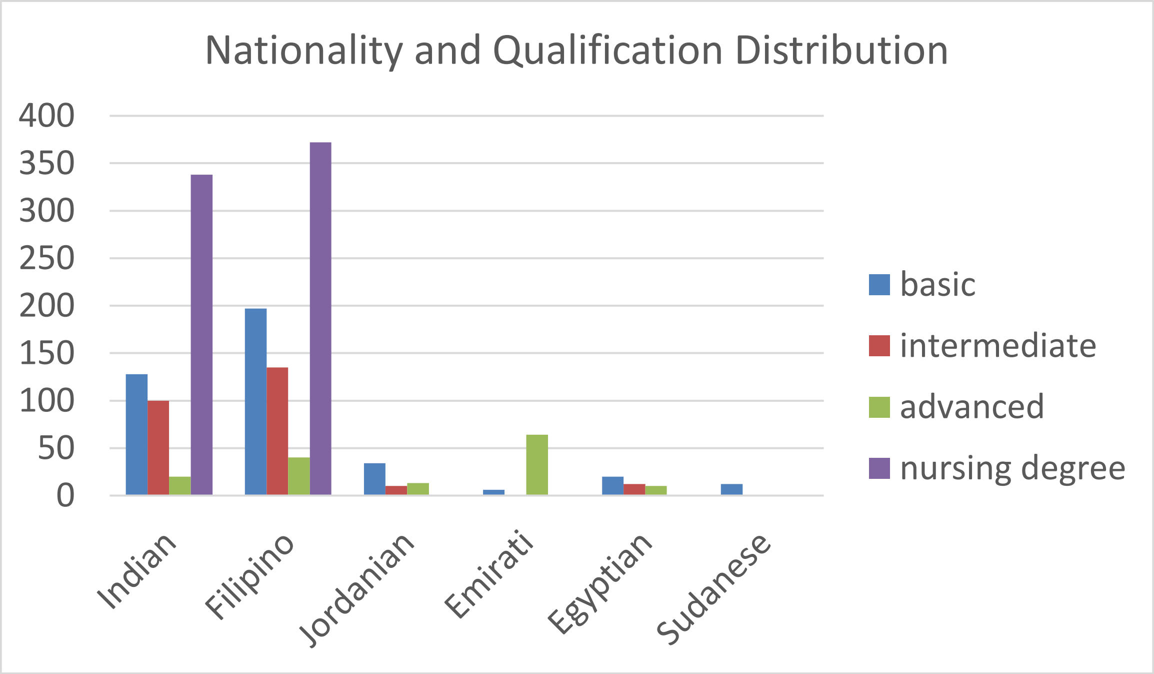

Figure 3.5. Nationality and qualification distribution

The 823 emergency care providers work in various departments such as dispatch, scheduling and training although the majority are directly involved in patient care.

The unique blend of the various professional qualifications, nationalities and cultures at DCAS made it a suitable environment in which to conduct this research study. The target population for the study was all the emergency care providers actively involved in patient care.

3.4.1 Sampling Method

Non-probability sampling was employed with the survey being sent out to emergency care providers working in the field. The survey software package Grapevine Surveys was utilized to distribute the survey. This is the software package used by the Dubai Corporation of Ambulance Services to run internal audits and to communicate with all of their staff. Permission was granted to use this software in order to facilitate the distribution of the online survey. This was done with assistance from the Strategy and Corporate Excellence Office. The survey was sent to 823 emergency care providers who work in the field.

Letters of information and consent were sent via email with a link to the survey. Participation in the survey was voluntary and assurance was given that participation in the study will not negatively affect the participant's professional career or employment. All responses were collected anonymously and respondents were therefore not personally identifiable. The letter of information and consent had the Durban University of Technology letter head and the contact details of the supervisor, Institutional Research Ethics Administrator and the Director: Research and Postgraduate Support to allay any concerns of coercion.

3.4.2 Sample Population

According to an online sample size calculator using a confidence level of 95% with a 5% margin of error the sample size should have been 267 participants (Fluidsurveys.com). Participation was voluntary and all participants were given an information letter to read. They were also required to complete and sign a consent form (Annexures A and B). The participants were informed about the research and given instructions on how to complete the survey. All the participants remain anonymous with measures being taken to ensure their anonymity. The completed consent forms and questionnaires were saved and coded to maintain anonymity as well as to identify the responses in the event of a participant choosing to withdraw from the study.

3.4.3 Inclusion Criteria

All the participants were emergency care providers who had come into direct contact with patients as part of their duties. These emergency care providers had had a minimum of one year’s continuous, full-time experience with patient care and had had to deal with death and dying.

3.4.4 Exclusion Criteria

Emergency care providers who were not directly involved in patient care were excluded from the study as were emergency care providers who had less than a year’s continuous, full time experience with patient care as well as emergency care providers who had not yet encountered a situation that required them to deal with a dead or dying patient.

3.5 DATA COLLECTION TOOL

A set of survey questions were formulated by the researcher to collect the requisite data (Annexure C). This questionnaire contained questions pertaining to gender, age, qualification, nationality, religion, and years of experience to establish the demographics and statistical data of the participants. The questionnaire was based on relevant literature and other studies conducted on the topic of death, dying and bereavement and included both close-ended and fixed alternative questions with multichotomous, dichotomous and scaled questions. A few contingency questions were also asked in order to provide more detail when required.

3.6 PILOT TESTING

A pilot study is synonymous with a feasibility study (Thabane et al., 2010). Grimm (2010) points out that a pilot study is also useful to “detect any problem with the questionnaire design which may lead to ambiguity of words, misinterpretation of questions, inability to answer a question, sensitive questions, and many other problems associated with the questionnaire” (Grimm, 2010). The validity of the data collected using a questionnaire depends on shared assumptions and an understanding of the questions and response categories (Bowling, 2009: 301). Research has shown that questions may be misinterpreted with this affecting the results of the study (Tanur, 1994; Mallinson, 1998: 306). Pilot testing may also test the process of administering the survey although this was not the purpose of the pilot study conducted in this study. The pilot study questionnaires were printed and distributed manually, while the main survey was sent out electronically.

For the pilot study the questionnaire was printed out and delivered to a clinical instructor at the National Ambulance Service in Abu Dhabi. A soft copy was also emailed to him in case he had to print more copies. He handed the questionnaire to a field shift supervisor who administered the questionnaire during four different shift changes. He gave the questionnaire to whoever was available and waited for them to complete the survey and return it. A total of 25 surveys were completed and returned in the same way. The survey administrator was also questioned regarding the non-verbal behaviour of the participants while they completed the survey and also the time taken to complete the survey.

In addition, the researcher asked five emergency care providers with more than 15 years of experience each to complete the survey and provide feedback on the data collection tool. A total of 30 questionnaires were reviewed in the pilot study and discussions were held with the five experienced emergency care providers.

The data collected in the pilot study was not included in the main study and neither were the participants who took part in the pilot study involved in the main study.

The pilot study highlighted several issues which included simple formatting, number anomalies, and the use of redundant words, word changes and missing responses. The questionnaire was completed by 23 males and seven females. The predicted time of completion was found to be nearly five minutes shorter than had been anticipated and, so, the time was adjusted on the information letter. The wording of some questions was changed to eliminate confusion while the ‘not applicable’ option was added for two of the questions. Some of the questions were aimed specifically at the Dubai Corporation of Ambulance Services and were, thus, left blank by six respondents who worked for National Ambulance. A detailed report of the pilot study is included in the list of annexures at the end of the dissertation (annexure G – pilot study report).

3.7 RELIABILITY AND VALIDITY OF DATA COLLECTION TOOL

The data collection tool (Annexure C) was developed based on surveys that had already been published and which had produced reliable and valid data in similar studies. Templer’s death anxiety scale is a popular measure of death attitudes and has been revised to the Death Anxiety Scale – Extended and, more recently, to the Death Anxiety Scale – New (Neimeyer, 1994; Fortner et al., 1999: 388). This scale, together with Bugen's Coping with Death Scale, has led many contemporary researchers to develop numerous other tools such as Wong's Death Attitude Profile – Revised, Robbin's Death Competence Scale and multiple other scales that are based on these pioneering scales (Gesser et al., 1988: 113; Robbins, 1991: 284; Claxton-Oldfield, Crain and Claxton-Oldfield, 2007; Meagher and Balk, 2013: 30). The questionnaire includes demographic questions as well as certain specific questions related to the research topic. As already mentioned, it had been subjected to pilot testing.

3.8 RESEARCH PROCESS

A letter requesting permission to conduct the survey research was sent to both the CEO of the Dubai Corporation for Ambulance Services and the Head of the Medical and Research Studies Unit (Annexure E). A copy of the approved proposal, together with the ethical clearance, were also submitted to the DCAS research committee in order to obtain their organisational and in-service ethics approval. Once the project had been approved and permission granted to carry out the study, arrangements were made with the head of the operations, the strategy department and the research department to send out the survey and to encourage a positive response rate.

A letter of information was sent to all the participants to outline the details of the study and to remind the candidates that participation in the study was both voluntary and anonymous. Once the information letter had been read and written consent obtained the participants were able to access and complete the online survey. The language used to communicate in the service is English because of the diverse population and, thus, all the documentation was provided in English.

The researcher had several meetings with the various heads of department to explain the research project and to invite their support in order to encourage a good response rate. The link was also sent via WhatsApp as all of the emergency care providers were members of WhatsApp groups while the WhatsApp platform is routinely used for communications between the ambulance service management and the ambulance crew.

3.8.1 Data Collection

Once the research project had received full ethics clearance from the Durban University of Technology Institutional Research Ethics Committee (Annexure E) and the required gatekeeper approval (Annexure F) had been received the data collection commenced.

The Dubai Corporation for Ambulance Services uses an electronic system to conduct surveys within the organisation. The researcher obtained permission to use this avenue to access the total target population.

The calculated minimum number of responses required was 267. However, this was exceeded within the first day of going live and, on the second day, after consultation with the project supervisors and the statistician, the researcher pulled the results for coding and analysis. Measures were taken to ensure that the collection of the data did not interfere with the ambulance services operations and service delivery in any way.

3.8.2 Data Analysis

The data collected from the responses was analysed using the IBM Statistical Package for Social Sciences (SPSS) version 25.0. The expertise of a professional statistician was also solicited to assist with the data analysis.

The descriptive statistics are presented in the form of graphs, cross tabulations and other figures for the quantitative data that was collected. Inferential statistic techniques such as correlations and chi square test values were used and interpreted using the p-values. Factor analysis was also conducted for the purpose of reducing the data obtained from Section F of the survey. This allowed the researcher to represent the answers to all the questions in this section with a smaller number of components/factors in order to provide an adequate measure of death attitude. Principle component analysis was used to extract the factors and Varimax with Kaiser Normalisation was then used as the rotation method. This is an orthogonal rotation method which is used in order to minimise the number of variables that have high loadings on each factor, thus simplifying interpretation.

3.9 ETHICAL CONSIDERATIONS

This study followed the principles of beneficence, non-maleficence, and respect for autonomy, fairness, truthfulness and justice. The Durban University of Technology

Faculty of Health Sciences' policy document contains guidelines for the ethical considerations in research. These guidelines were adhered with consent to conduct the study being obtained from the ethics committee of the Dubai Corporation of Ambulance Services. No patient data was used in the study and all participants' identities remained anonymous. The raw data was securely accessed by the researcher, the supervisors and the statistician to ensure that there was no risk of compromising the dignity of any individual. Care was taken to limit the questions in the survey to the issue of the preparation of emergency care providers and not to make mention of any particular incidents of which the memory may have caused stress. The participants were provided with an information brochure for traumatic stress disorder signs and symptoms as well as the contact details for a professional counsellor in case the subject matter elicited an emotional response.

3.10 CONCLUSION

This chapter described the attempts made by the researcher to ensure that the study presented accurate, unbiased, interpretable, and replicable evidence. The chapter also provided justification for the research design used and its validity. The setting of the study, population and sample were discussed and the data collection and data analysis process described. The pilot study findings and some of the required adjustments to the data collection tool were discussed and, finally, the ethical considerations to ensure the study's ethical integrity were presented.

The following chapter presents the results of the statistical analysis.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

This chapter presents the results of the study and discusses the findings obtained from the questionnaires, which were administered with the aim of investigating the extent to which emergency care providers are prepared to deal with death, dying and bereavement. In addition, the ultimate aim was to recommend strategies that would enable providers to cope with this issue sensitively and efficiently in the prehospital environment. The questionnaire consisted of 57 items, each with a measurement at either a nominal, ordinal or scale level. The questionnaire comprised six sections, intended to collect data pertaining to biographical particulars, educational and professional training, exposure to death, dying and bereavement in the workplace, personal exposure to death, dying and bereavement, death education and death attitude. The arrangement of these sections in the questionnaire will provide the framework for this chapter.

4.2 SECTION A: BIOGRAPHICAL DATA

This section summarises the biographical characteristics of the respondents.

Overall, the ratio of male to female was found to be approximately 4:1 (n = 382; 78.1%): (n = 107; 21.9%). More than half (n = 266; 54.4%) of the respondents indicated being between 26 and 35 years old with only 1.4% (n = 7) indicating 25 years of age or younger.

Table 4.1 Gender distribution by age

Gender	Age	Count	Percentage of age	 of gender	 of total
Female	≤ 25	6	85.7	5.6	1.2
	26-35	52	19.5	48.6	10.6
	36-45	41	28.7	38.3	8.4
	≥45	8	11.0	7.5	1.6
	Total	107	21.9	100.0	21.9
Male	≤ 25	1	14.3	0.3	0.2
	26-35	214	80.5	56.0	43.8
	36-45	102	71.3	26.7	20.9
	≥45	65	89.0	17.0	13.3
	Total	382	78.1	100.0	78.1
Total	≤ 25	7			1.4
	26-35	266			54.4
	36-45	143			29.2
	≥45	73			14.9
	Total	489			100.0

In the age category of 26 to 35 years, n = 214 (80.5%) were male and n = 52 (19.5%) were female. Among the males only, 56% (n = 214) were between the ages of 26 and 35 years. This category of males formed 43.8% (n = 214) of the total sample, with a significantly lower number (n = 73; 14.9%) of respondents falling into the 45 years and older category. Among the females only, 7.5% (n = 8) reported being 45 years and older.

Individually, gender and age are thus skewed ($p < 0.05$).

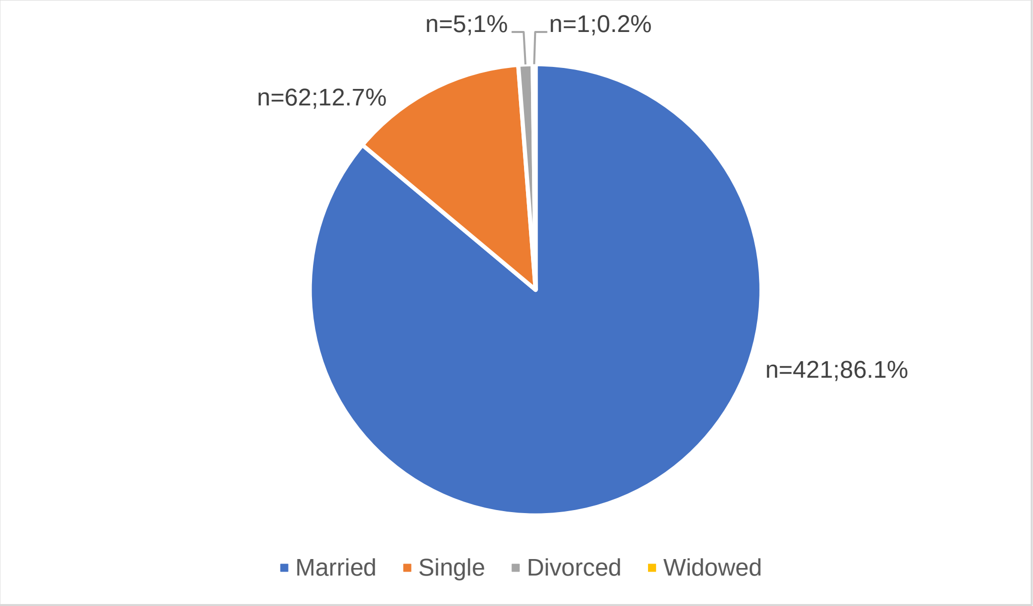

Figure 4.1 Marital status of respondents

Significantly more respondents (n = 421; 86.1%) indicated that they were married ($p < 0.05$), while 12.7% (n = 62) of respondents were single, five (1.0%) were divorced and one respondent (0.2%) was widowed.

4.3 SECTION ANALYSIS

The following section analyses the scoring patterns of the respondents per variable per section. The results are initially presented using summarised percentages for the variables that constitute each section and then further analysed according to the significance of the statements within the context of the study.

4.3.1 Section B: Education and Professional Training

In this section of the questionnaire, the researcher sought to explore the experience, as well as the types and levels of education and training that the respondents had. Cross tabulation of the results for the questions: “How long ago did you obtain your first clinical qualification?” and “How many years of clinical experience do you have?” showed that, individually, more respondents had more years of experience, corresponding to the period when the qualification was obtained ($p < 0.05$). As may be seen from Figure 4.2, the patterns correspond in terms of years of experience and years of first qualification.

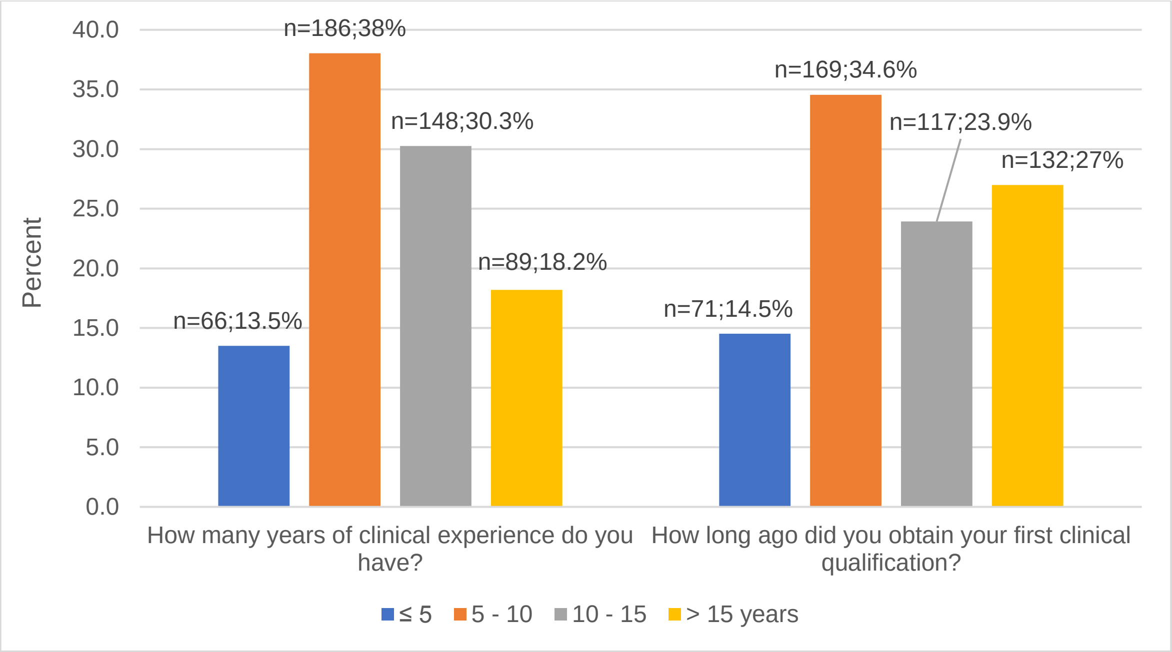

Figure 4.2 **Cross tabulation Question 4 and Question 5**

As Table 4.2 below indicates, a significant relationship exists between the number of years of clinical experience and how long ago the first clinical qualification was obtained ($p < 0.001$). Accordingly, a chi-square value of 258.389 was found with 9 degrees of freedom.

Table 4.2 **Chi-square test Question 4 vs Question 5**

Chi-square tests			
	Value	df	Asymptotic significance (2-sided)
Pearson chi-square	258.396[a]	9	0.000
Likelihood ratio	291.471	9	0.000
Linear-by-linear association	147.198	1	0.000
N of valid cases	489		

4 cells (25.0%) have expected count less than 5. The minimum expected count is 1.02.

Figure 4.3 indicates that the majority (n = 265; 55%) of respondents held a nursing qualification, with only a small portion (n = 32; 6.6%) having an EMS qualification only. Approximately 40% (n = 185) of respondents reported having both a nursing and an EMS qualification ($p < 0.05$).

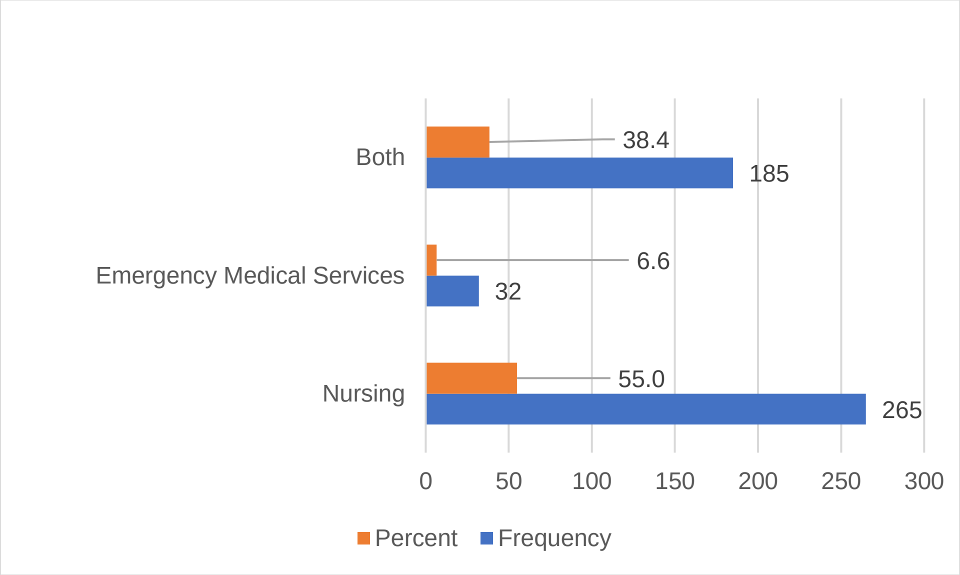

Figure 4.3 Clinical qualifications

As indicated in Figure 4.4, a significant number of respondents (n = 406; 83.7%) held a Bachelor's degree in nursing ($p < 0.05$), while the remaining 13.4% (n = 65) who held nursing qualifications, had either a nursing certificate, an associate degree, a diploma, a higher diploma or a postgraduate qualification.

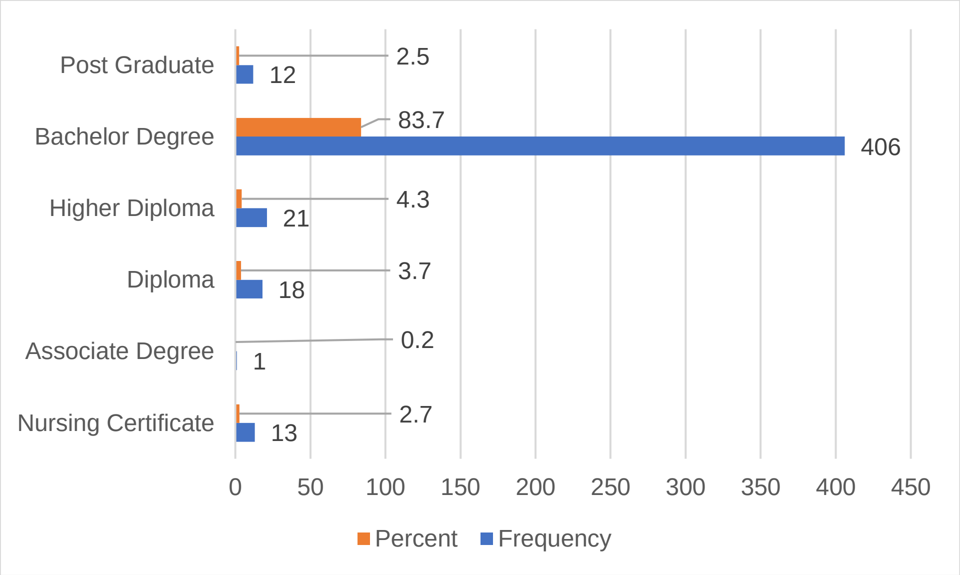

Figure 4.4 Nursing qualifications

Two-thirds of the respondents (n = 307; 65.0%) reported holding a Basic EMT Certificate, with smaller numbers for each of the other options ($p < 0.05$). Only 11.9% (n = 56) of the respondents reported holding a Bachelor's degree in EMS (Figure 4.5).

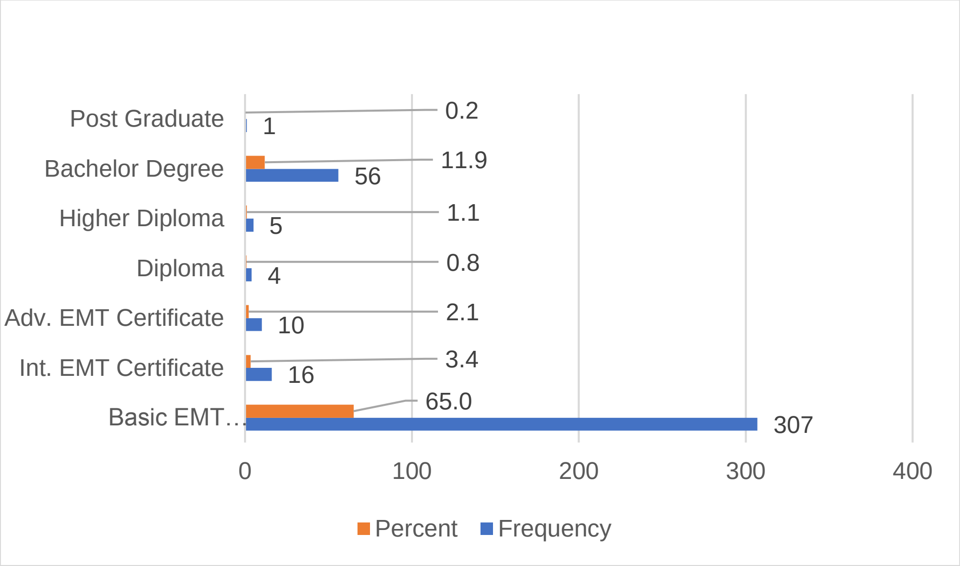

Figure 4.5 Emergency medical services qualifications

Question 9 of the questionnaire asked respondents who specified “Other” in answer to question 6 to specify what qualifications they held other than nursing, EMS or both. Consequently, all the respondents (n = 496) restated their qualifications and listed additional certifications such as Basic Life Support, Advanced Cardiac Life Support, Paediatric Advanced Life Support, Basic and International Trauma Life Support and other certificate courses, ranging in duration from one to three days. Additionally, one respondent (0.2%) reported having completed a three-year electronic technician course, one (0.2%) was a general physician with a diploma in surgery, one (0.2%) had a pharmacy qualification, one (0.2%) was a phlebotomist and one (0.2%) had a qualification in rehabilitative medicine.

4.3.2 Section C: Exposure to Death, Dying and Bereavement in the Workplace

In this section, the questions examined the extent to which the respondents had been exposed to death, dying and bereavement as part of their daily work and whether this exposure had had any adverse effects on them. The researcher also wanted to explore whether the respondents felt comfortable with their exposure and what support structures were in place for those who need them.

Most respondents (n = 396; 80%) reported working with the emergency response ambulances. These ambulances are posted across Dubai in various locations, including the airports and harbours. Respondents who specified working at the airport (n = 33; 6.6%) were added to the respondents who selected emergency response ambulance. Respondents who worked in the first responder units (n = 16; 3%), female emergency unit (n = 4; 0.8%), helicopter emergency medical services (n = 10; 2.1%) and doctor response unit (n = 3; 0.6%) make up the highest qualified medical personnel in the field and made up 6.6% (n = 33) of the total sample.

Table 4.3 Department within DCAS

Department	Frequency	Percent
Emergency response ambulance	396	80.0
First responder unit	16	3.0
Medical intensive care unit	32	6.4
Helicopter emergency medical services	10	2.1
Neonatal and paediatric unit	3	0.6
Disaster response team	6	1.2
Doctor response unit	3	0.6
Desert response unit	1	0.2
Motorcycle responder	1	0.2
Bicycle responder	5	1
Dispatch	17	3.4
Female emergency unit	4	0.8
Marine response	2	0.4
Total	496	

Approximately 87% (n = 426) of the respondents indicated that they received fewer than ten calls per shift ($p < 0.05$), while more than half of the respondents (n = 276; 55.6%) reported attending to five to ten calls per shift. Respondents who worked in units that do not transport patients to hospital, such as the responder unit and the motorbike unit, would have a quicker turnaround time and would therefore be able to attend to more calls. Accordingly, they may account for the 26 (5.2%) and 39 (7.9%) respondents who reported attending to between 11 and 15 calls and more than 15 calls, respectively, in a shift. Units that carry out inter-facility patient transfers are likely to spend more time on a call and will therefore attend fewer calls during a shift. In contrast, 150 (30.2%) of the respondents reported attending to fewer than five calls in a shift (Figure 4.6).

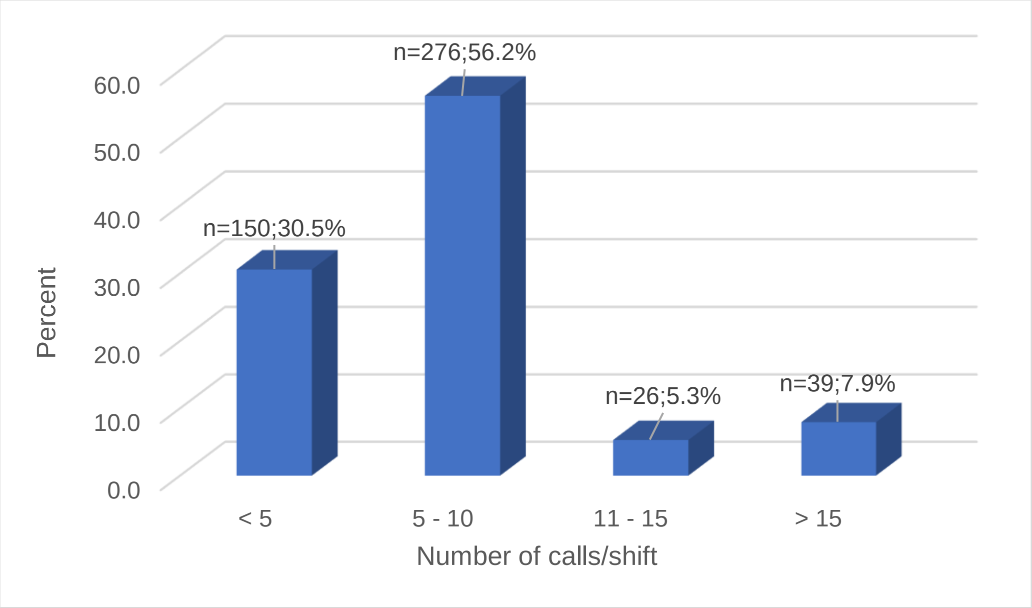

Figure 4.6 **Average number of calls attended to in a shift**

The majority of respondents (n = 440; 89.6%) indicated attending to an average of fewer than three calls per shift that involve a death ($p < 0.05$).

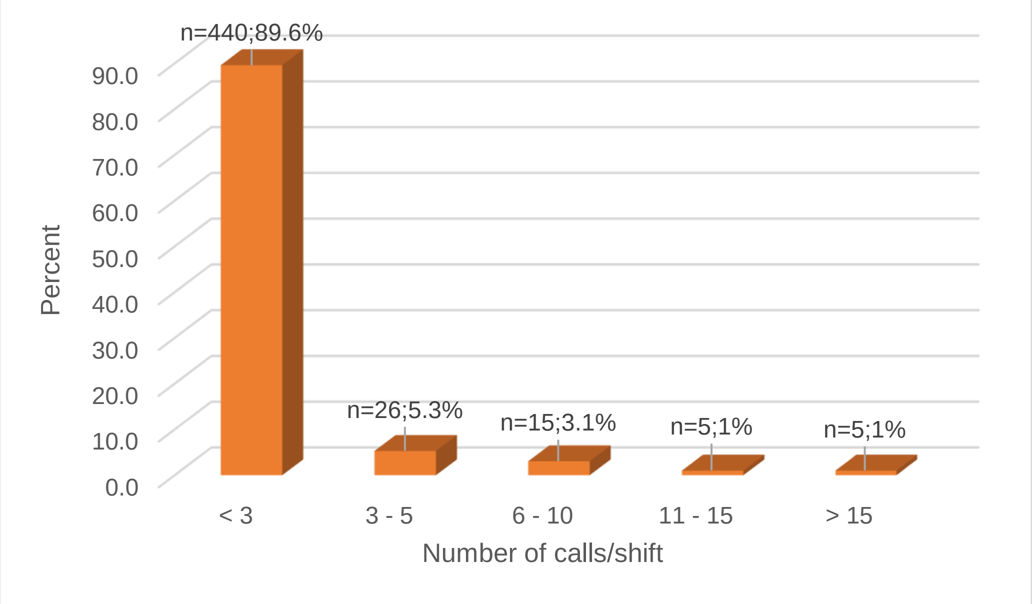

Figure 4.7 **Number of calls involving a death**

A significant number of respondents (n = 364; 74.1%) reported being able to recall their first emergency response that involved a dead or dying patient ($p < 0.05$). By contrast, 127 (25.9%) respondents could not recall their first emergency response that involved a dead or dying person and five (1%) did not answer the question.

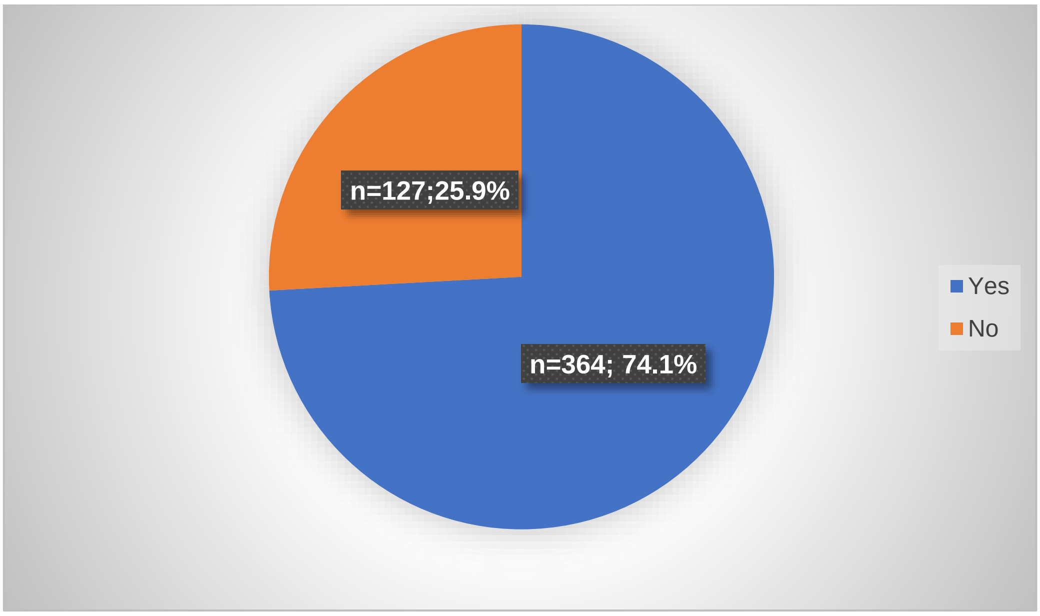

Figure 4.8 **Percent of respondents who can recall first case involving death or dying**

Of the 364 (74.1%) respondents who could recall their first emergency response involving a dead or dying patient, only 59 (11.9%) reported not feeling adequately prepared to deal with dead or dying patients ($p < 0.05$).

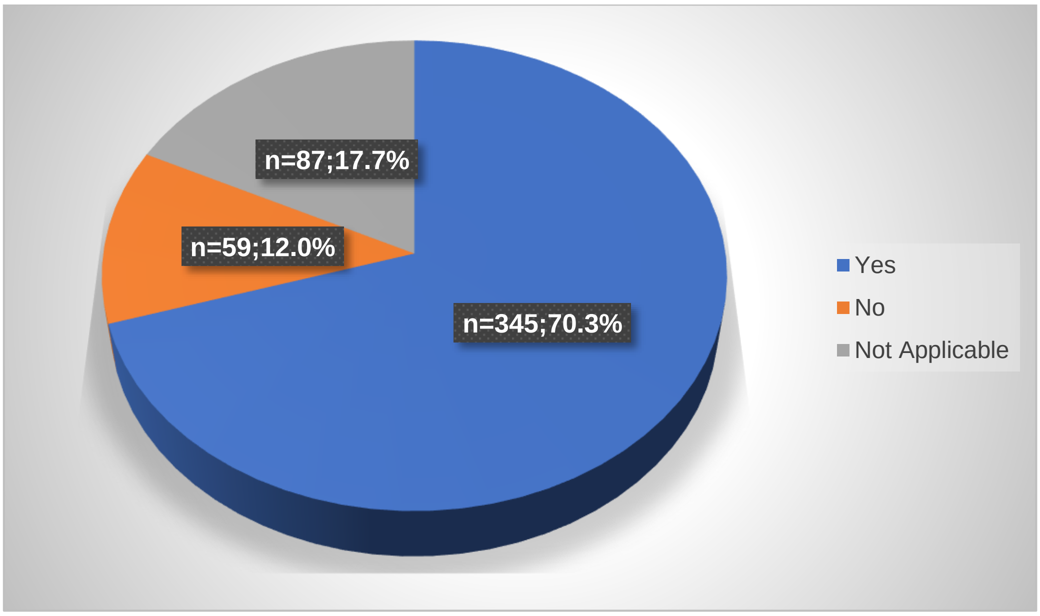

Figure 4.9 **Respondents who felt adequately prepared to deal with dead or dying patients**

Although more than half of the respondents (n = 288; 58.7%) reported being allowed to declare death in the field, a significant number (n = 203; 41.3%) reported that they were not allowed to do so (Table 4.4) ($p < 0.05$).

Table 4.4 Are you allowed to declare death in the field?

	Frequency	Percent
Yes	288	58.7
No	203	41.3
Total	491	100.0

As Table 4.5 shows, no significant difference was found between the number of respondents who answered yes (n = 249; 50.7%) and no (n = 242; 49.3%) to the question on whether they had conducted death notification in the field (p = 0.752).

Table 4.5 Have you had to conduct death notification in the field?

	Frequency	Percent
Yes	249	50.7
No	242	49.3
Total	491	100.0

More respondents (n = 220; 44.8%) reported feeling comfortable making death notifications than those who were not (n = 198; 40.4%), although approximately 15% (n = 73) indicated uncertainty in this regard (p < 0.05).

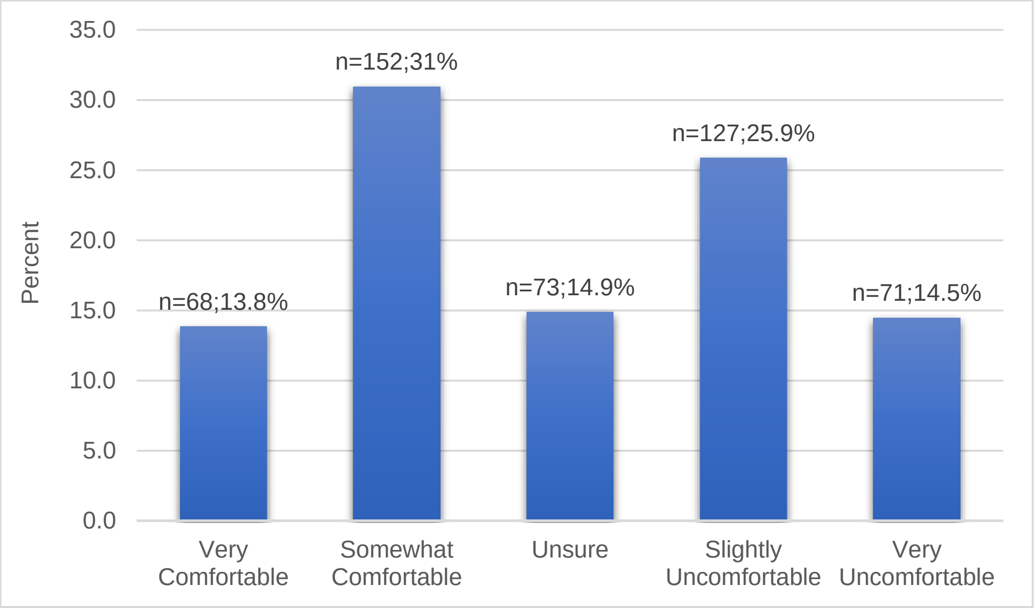

Figure 4.10 Ease of making death notifications

The majority of respondents (n = 433; 88.2%) stated that they had a protocol, guide or procedure to follow when dealing with death in the field, while 58 (11.8%) respondents reported not having one (Table 4.6) ($p < 0.05$).

Table 4.6 Do you have a protocol, guide or procedure to follow for deaths in the field?

	Frequency	Percent
Yes	433	88.2
No	58	11.8
Total	491	100.0

Although 206 (42%) respondents (Table 4.7) reported that Dubai Corporation of Ambulance Services (DCAS) provides professional debriefing after a call involving a death, the majority (n = 285; 58%) stated that DCAS did not do so ($p < 0.05$).

Table 4.7 Does the service provide professional debriefing after a call involving a death?

	Frequency	Percent
Yes	206	42.0
No	285	58.0
Total	491	100.0

Approximately one-fifth (n = 25; 19.8%) of the respondents who had experienced an unpleasant incident as a result of a work-related death had done so in the last six months (Table 4.8). Individually, each variable displayed significantly different scoring patterns ($p < 0.05$).

Table 4.8 Effect of work-related death incident vs timing of incident

	Has any work-related death or dying incident ever bothered you so much that you have lost sleep, missed work, had nightmares, or had any other notable effect?
Yes – within the last 6 months	25
Percentage of YES	19.8
Percentage of N	5.1
Yes – longer than 6 months ago	101
Percentage of YES	80.2
Percentage of N	20. 6

➡

Table 4.8 cont'd

	Has any work-related death or dying incident ever bothered you so much that you have lost sleep, missed work, had nightmares, or had any other notable effect?
Subtotal YES	126
Percentage of total	25.7
No	365
Percentage of N	74.3
Total	491

N=491

Of those respondents who reported being adversely affected by a work-related death or dying incident, only 4.1% (n = 20) indicated that they had received professional counselling ($p < 0.05$). This implies that 106 (84%) of the respondents who reported being adversely affected by such an incident had not received professional counselling.

Table 4.9 Did you receive professional counselling?

	Frequency	Percent
Yes	20	4.1
No	330	67.2
Not applicable	141	28.7
Total	491	100.0

The 20 (4.1%) respondents who had received counselling reported that this was provided by the DCAS ($p < 0.05$).

Table 4.10 Was counselling provided by the DCAS?

	Frequency	Percent
Yes	20	4.1
No	109	22.2
Not applicable	362	73.7
Total	491	100.0

A greater number of respondents (n = 344; 70.1%) thought that a counselling service should be provided by their employer ($p < 0.05$).

Table 4.11 Do you think that counselling should be provided by your employer?

	Frequency	Percent
Yes	344	70.1
No	32	6.5
Not applicable	115	23.4
Total	491	100.0

4.3.3 Section D: Personal Exposure to Death, Dying and Bereavement

Section D of the questionnaire contained just two questions, which asked whether the respondent had known someone who had died within the last year and what their relationship to that person or persons was.

In response, 292 (58.9%) of the respondents indicated that they knew someone who had died in the last year, while 40.1% (n = 199) indicated that they did not ($p < 0.05$).

Table 4.12 Has someone you know died within the last year?

	Frequency	Percent
Yes	292	59.5
No	199	40.5
Total	491	100.0

Twenty-three (4.6%) respondents reported the death of a parent, 14 (2.8%) reported the death of a sibling, one (0.2%) reported the death of a daughter and one (0.2%) reported that his wife had died. These may be considered close relatives and together signify that 7.5% (n = 39) of the total study population had experienced the death of a close relative. Other familial deaths included cousins (n = 18; 3.8%), nephews (n = 3; 0.6%), grandparents (n = 48; 9.6%) and uncles/aunts (n = 76; 15%). Sixteen (3.2%) of the respondents reported the death of a colleague, while 77 (15.5%) reported the death of a friend ($p < 0.05$).

Table 4.13 The person who died was a/an:

Relationship	Frequency	Percent
Parent	23	4.6
Sibling	14	2.8
Spouse	1	0.2
Cousin	19	3.8
Grandparent	48	9.6
Aunt/uncle	76	15.3
Friend	77	15.5
Colleague	16	3.2
Other: daughter	1	0.2
Nephew	3	0.6
Neighbour	4	0.8
Not applicable	181	35.4
No response	33	6.6
Total	496	100.0

4.3.4 Section E: Death Education

The majority of respondents (n = 316; 64.4%) reported that they had not received any formal education or training on death, dying and bereavement, while 175 (35.6%) reported that they had ($p < 0.05$).

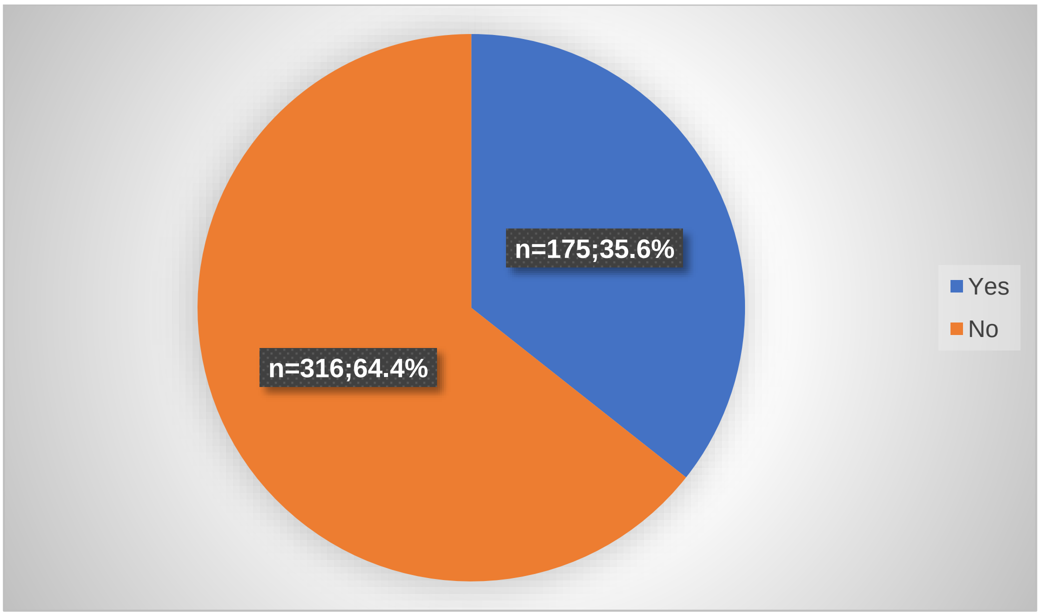

Figure 4.11 Received formal instruction or training

Around half (n = 87; 49.7%) of those who reported receiving formal instruction or training on death, dying and bereavement reported that the duration of this training was between one hour and a day, with just four (2%) reporting the duration of the training as being longer than five days ($p < 0.05$).

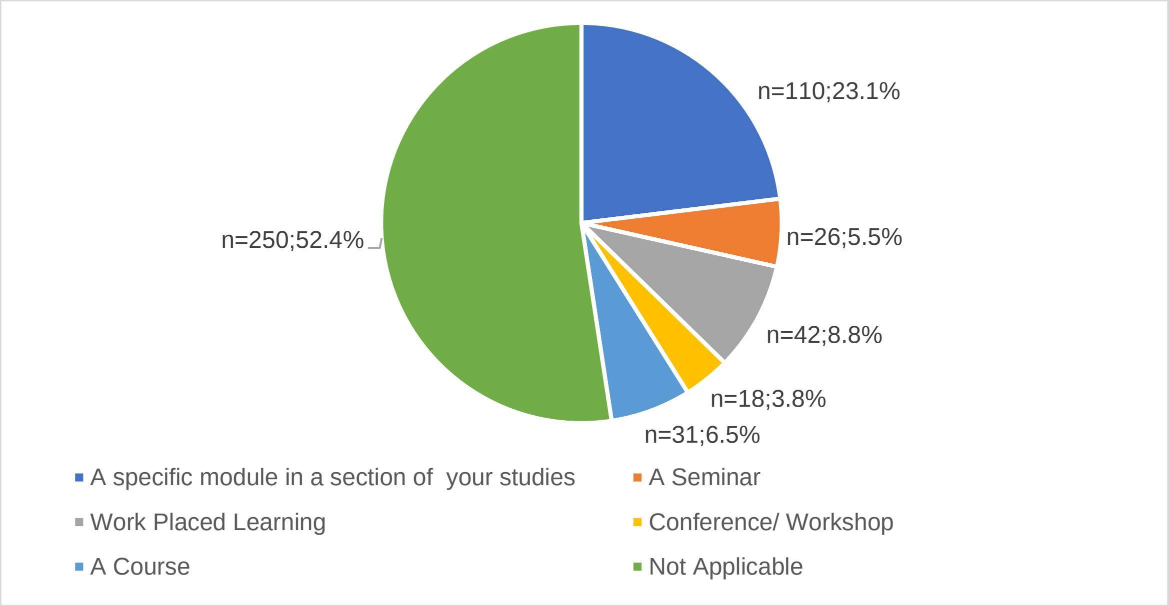

Figure 4.12 Location of training

Figure 4.12 above shows that of those who had received training on death, dying and bereavement (n = 175), the majority (n = 110; 23.1%) reported that it had formed part of a specific module in a section of their studies, with only 6.5% (n = 31) of these reporting having attended a course on death, dying and bereavement ($p < 0.05$).

In addition, Table 4.14 shows that of those who had received training on death, dying and bereavement (n = 175), more than half (n = 98; 56%) reported that the topic of coping with death and dying had been covered during their training, although only seven (4%) reported that death notification was covered. In addition, 14 (8%) respondents reported that end-of-life decision making and death documentation were covered in their instruction or training, and the topics of loss, grief and mourning and declaration of death were reported by 22 (12.6%) respondents as having been covered ($p < 0.05$). Twenty-four respondents did not answer this question.

Table 4.14 What topics were covered during your training on death, dying and bereavement?

Topic	Frequency	Percent
Coping with death & dying	98	20.8
Assessment & intervention	31	6.6
Loss, grief and mourning	22	4.7
Declaration of death	22	4.7
End-of-life decision making	14	3.0
Death documentation	14	3.0
Death notification	7	1.5
Critical incident debriefing	6	1.3
Not applicable	258	54.7
Total	472	100.0

Instruction or training on death and dying was offered mainly by nursing instructors (n = 124; 70.8%) and paramedic instructors (n = 65; 13.6%), with 11 (2.3%) respondents reporting receiving instruction or training from a specialist in death and dying and even fewer respondents (n = 3; 0.6% and n = 2; 0.4%) reporting receiving instruction from a grief counsellor and a social worker respectively (Table 4.15) ($p < 0.05$). Seventeen respondents left this answer blank.

Table 4.15 Who delivered the Instruction or training on death and dying?

	Frequency	Percent
Nursing instructor	124	25.9
Paramedic instructor	65	13.6
Psychologist	22	4.6
Specialist in death and dying	11	2.3
Grief counsellor	3	0.6
Social worker	2	0.4
Not applicable	252	52.6
Total	479	100.0

Twenty percent (n = 99) of the respondents reported that they had participated in a simulated death scenario, while the majority (n = 394; 79.9%) had not ($p < 0.05$). Three respondents did not answer this question.

Table 4.16 Have you participated in a simulated death scenario?

	Frequency	Percent
Yes	99	20.1
No	394	79.9
Total	493	100.0

As indicated in Table 4.17 below, 57 (11.5%) respondents reported that the simulation exercise was graded ($p < 0.05$), while three respondents did not respond to this question.

Table 4.17 Was the simulation exercise graded?

	Frequency	Percent
Yes	57	11.6
No	85	17.2
Not applicable	351	71.2
Total	493	100.0

A large number of participants (n = 377; 76.5%) reported not having participated in a simulation involving a conscious terminally ill or dying patient; by contrast, 116 (23.5%) reported that they had participated in such a simulation ($p < 0.05$).

Table 4.18 Have you participated in a simulation scenario involving a conscious terminally ill or dying patient?

	Frequency	Percent
Yes	116	23.5
No	377	76.5
Total	493	100.0

Seventy-seven (15.8%) respondents, as shown in Table 4.19 below, reported that the simulation exercise, involving a conscious terminally ill or dying patient, in which they participated was graded ($p < 0.05$). Ten respondents did not respond in this regard

Table 4.19 Was the simulation involving a conscious terminally ill or dying patient graded?

	Frequency	Percent
Yes	77	15.8
No	78	16.0
Not applicable	331	68.1
Total	486	100.0

Most participants (n = 427; 86.6%) reported not having participated in a simulated death notification scenario, with only 66 (13.4%) reporting having done so ($p < 0.05$). Three respondents did not answer the question.

Table 4.20 Have you participated in a simulated death notification scenario?

	Frequency	Percent
Yes	66	13.4
No	427	86.6
Total	493	100.0

As Table 4.21 below indicates, 43 (8.9%) respondents reported that the simulated death notification scenario that they participated in was graded ($p < 0.05$), while 12 respondents left the question unanswered.

Table 4.21 Was the simulation exercise involving death notification graded?

	Frequency	Percent
Yes	43	8.9
No	82	16.9
Not applicable	359	74.2
Total	484	100.0

More than half of the respondents (n = 257; 52.1%) reported not having to undertake any other graded assessments on death and dying during their studies, while 67 (13.6%) reported that they had been required to do so ($p < 0.05$).

Table 4.22 Did you undertake any other graded assessments on death and dying during your studies?

	Frequency	Percent
Yes	67	13.6
No	257	52.1
Not applicable	169	34.3
Total	493	100.0

The respondents who indicated “yes” in response to whether they had other graded assessments in relation to death and dying generally mentioned their nursing studies (n = 24; 4.8%), while the majority indicated “not applicable” in response to the request for them to specify the other courses (n = 446; 89.9%). Four (0.8%) respondents specifically mentioned a “post mortem care, palliative care for the dying” course.

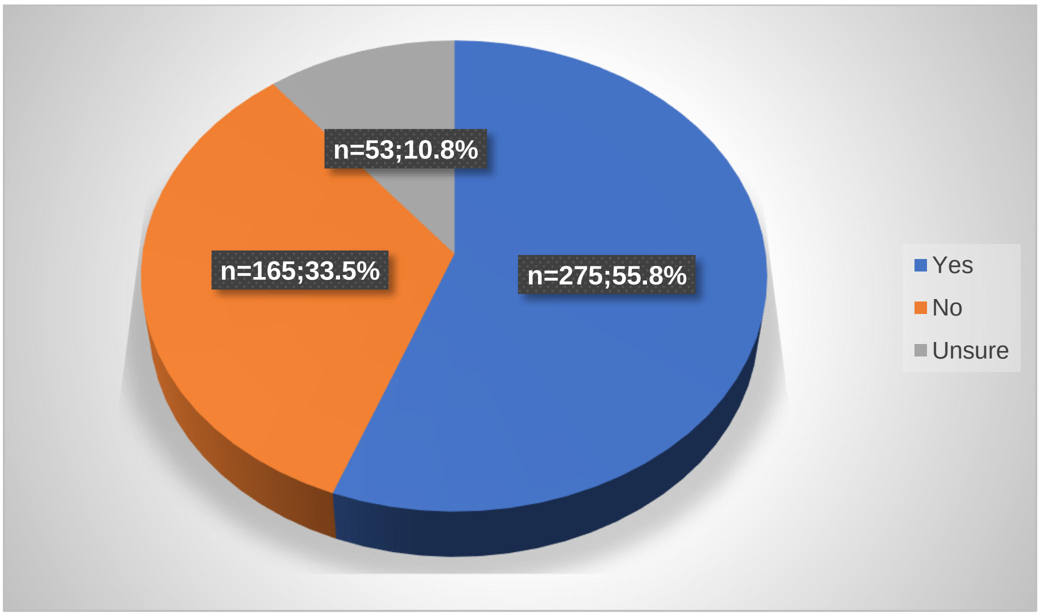

Figure 4.13 Attend a course on death, dying and bereavement

More than half of the respondents (n = 275; 55.4%), as illustrated in Figure 4.13, reported that they would attend a course on death, dying and bereavement if it were available, with 165 (33.5%) stating that they would not ($p < 0.05$). Fifty-three (10.8%) respondents were unsure about whether they would attend a course on death, dying and bereavement.

Most of the respondents (n = 351; 70.8%) selected the “all of the above” option when asked what they would like to learn more about, but 184 (37.1%) specifically indicated coping with death and dying as a topic ($p < 0.05$). One (0.2%) person stated that they would like to learn more about dealing with crime-related deaths, one (0.2%) stated that they would like to learn about preparing a last will and testament and one (0.2%) stated that they wanted to know more about notifying the Dubai Health Authority (DHA) when a death occurred. Figure 4.14 below shows the distribution of the topics that respondents would like to learn more about selected.

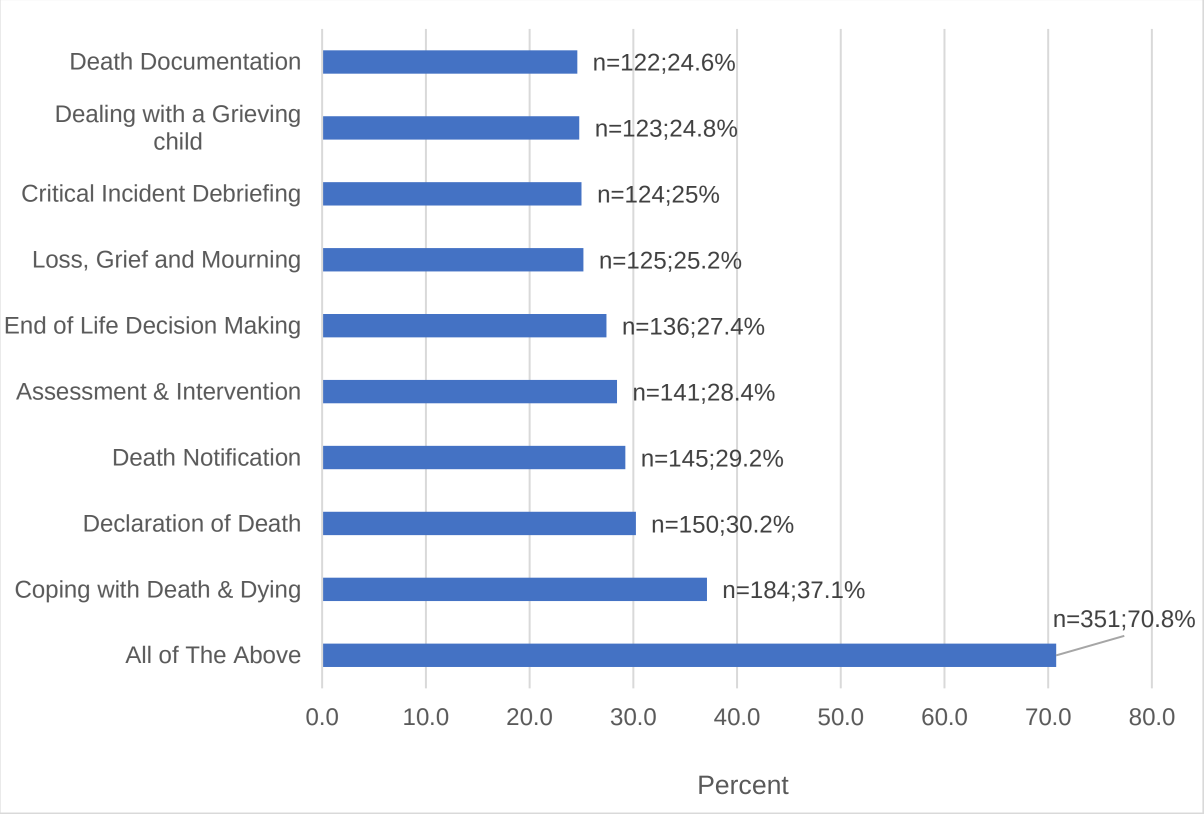

Figure 4.14 Topics that respondents would like to learn more about

4.3.5 Section F: Death Attitude

In this section, the researcher will present the findings obtained from Section F of the questionnaire. Accordingly, various tests, correlation studies, cross tabulations and factor analysis were carried out to examine the participants’ attitudes towards death. A five-point Likert scale was designed to measure the participant’s level of agreement with 16 statements regarding death. These statements were adapted from various scales that are widely used to measure death anxiety and death attitude (Gesser et al., 1988; Robbins, 1991; Neimeyer, 1994; Fortner et al., 1999; Claxton-Oldfield et al., 2007).

4.3.5.1 Reliability Statistics

In research, reliability and validity are important in relation to precision. Reliability implies consistency, while a test is deemed valid if it accurately measures what it is supposed to measure. Internal reliability was computed by taking several measurements of the same subjects. A reliability coefficient of 0.70 or higher is deemed to be "acceptable".

The table below reflects the Cronbach's alpha score for items in Section F of the questionnaire.

Table 4.23 Cronbach's alpha score for Section F

Cronbach's Alpha	N of Items
0.678	16

The reliability score approximates the recommended Cronbach's alpha value. Thus, this indicates a degree of acceptable, consistent scoring for this section of the research.

4.3.5.2 Likert Scale Response Analysis

To determine whether the scoring patterns for each statement differed significantly for each option, a chi-square test was carried out. The null hypothesis claims that similar numbers of respondents scored across each option for each statement (one statement at a time). The alternative states that there is a significant difference between the levels of agreement and disagreement. In addition, a binomial test was used to determine whether the levels different significantly from the level of disagreement (cut-off value = 4). Subsequently, as Table 4.24 indicates, all of the values show significance. This means that there was a difference in the scoring between Agree and Unsure, versus Disagreement. The sig. values (p-values) are lower than 0.05 (the level of significance), which implies that the distributions were not similar. That is, the differences between the way respondents scored (agree, unsure, disagree) were significant. These results are displayed in Table 4.24 below.

Table 4.24 Summary of the scoring patterns for Section F

	Strongly agree Count (Row N %)	Agree Count (Row N %)	Unsure Count (Row N %)	Disagree Count (Row N %)	Strongly disagree Count (Row N %)	Mean
F42 The thought of death scares me	37 (7.5)	157 (31.7)	76 (15.3)	126 (25.4)	100 (20.2)	3.19
F43 Suicide is never the answer	386 (77.8)	65 (13.1)	17 (3.4)	4 (0.8)	24 (4.8)	1.42
F44 I would like to die in my sleep	78 (15.7)	85 (17.1)	168 (33.9)	67 (13.5)	98 (19.8)	3.04
F45 I hate the sound of the word “death”	47 (9.5)	124 (25.0)	107 (21.6)	146 (29.4)	72 (14.5)	3.15
F46 Euthanasia should be legal	54 (10.9)	103 (20.8)	175 (35.3)	84 (16.9)	80 (16.1)	3.07
F47 I understand death	190 (38.3)	221 (44.6)	50 (10.1)	19 (3.8)	16 (3.2)	1.89
F48 I would like to die before my friends and family	49 (9.9)	83 (16.7)	223 (45.0)	74 (14.9)	67 (13.5)	3.05
F49 I think death will be painful	97 (19.6)	126 (25.4)	187 (37.7)	48 (9.7)	38 (7.7)	2.60
F50 I would like my organs to be donated when I die	134 (27.0)	138 (27.8)	144 (29.0)	35 (7.1)	45 (9.1)	2.43
F51 I have thought about my death	47 (9.5)	134 (27.0)	151 (30.4)	94 (19.0)	70 (14.1)	3.01
F52 I have thought about my funeral plans	27 (5.4)	101 (20.4)	165 (33.3)	119 (24.0)	84 (16.9)	3.27
F53 I have thought about the death of my loved ones	41 (8.3)	127 (25.6)	143 (28.8)	103 (20.8)	82 (16.5)	3.12
F54 I avoid discussing death	51 (10.3)	141 (28.4)	108 (21.8)	148 (29.8)	48 (9.7)	3.00
F55 I think about death more since I became an emergency care provider	58 (11.7)	133 (26.8)	119 (24.0)	119 (24.0)	67 (13.5)	3.01
F56 I feel life is too short	114 (23.0)	179 (36.1)	85 (17.1)	82 (16.5)	36 (7.3)	2.49
F57 I believe that there is life after death	206 (41.5)	128 (25.8)	107 (21.6)	23 (4.6)	32 (6.5)	2.09

Note: *χ^2 - all p<0.01; ** Binomial test – p<0.01 (cut off = 4)

The following patterns were observed and are illustrated in Figure 4.15:

- Some statements show (significantly) higher levels of agreement, whilst other levels of agreement are lower (but still greater than levels of disagreement).
- Eight (50%) statements show a high level of uncertainty.
- Six statements indicate higher levels of disagreement.
- The significance of the differences is tested and displayed in Table 4.24.

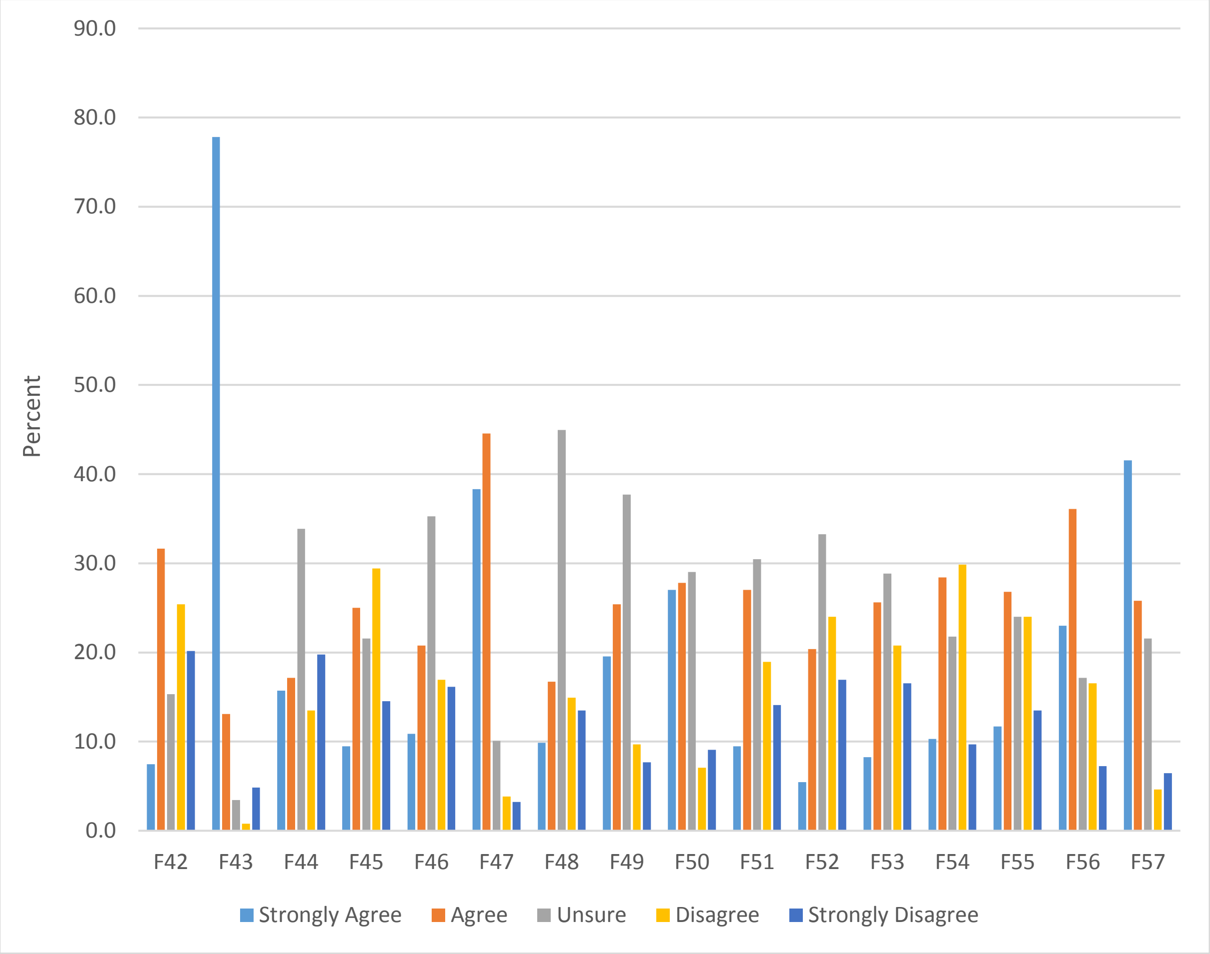

Figure 4.15 Responses to questions in Section F of questionnaire

One hundred and ninety-four (39.1%) respondents reported that the thought of death scares them (F42), while 226 (45.5%) disagreed with this statement and 76 (15.1%) reported being unsure ($p < 0.05$).

There was substantial agreement (n = 451; 90.9%) that suicide is never the answer, with 17 (3.4%) respondents indicating that they were “unsure” in this regard and 28 (5.6%) respondents disagreeing with the statement ($p < 0.05$).

A high level of uncertainty was displayed regarding whether participants would like to die in their sleep, with 168 (33.9%) indicating “unsure”, 78 (15.7%) strongly agreeing and 98 (19.8%) strongly disagreeing ($p < 0.05$).

A small percentage (9.5%; n = 47 and 14.5%; n = 72) of respondents strongly agreed and strongly disagreed respectively with the statement: “I hate the sound of the word death.” Most respondents either agreed (n = 124; 25%), disagreed (n = 146; 29%) or were unsure (n = 107; 21.6%) ($p < 0.05$).

Respondents were almost evenly split between agreeing (n = 157; 31.7%) and disagreeing (n = 164; 33%) with the statement that euthanasia should be legal (F46). Of these, 175 (35%) stated that they were unsure about whether euthanasia should be legal or not ($p < 0.05$).

Just under 83 percent (n = 411) of respondents reported that they understand death, selecting agree (n = 221; 44.6%) and strongly agree (n = 190; 38.3%) for question 47 (F47) in the questionnaire. A much smaller percentage (7%; n = 35) disagreed with the statement and 50 (10.1%) were unsure about their understanding of death.

Nearly half (n = 223; 45%) of the respondents were unsure whether they would like to die before their friends and family, with the balance of respondents being almost evenly split (n = 141; 25.6% agree and n = 132; 28.4% disagree) on either side of the scale ($p < 0.05$).

A significant number of respondents (n = 223; 45%) thought that death would be painful, while 187 (37.7%) were unsure. A much smaller number of respondents (n = 86; 17.4%) did not think that death would be painful ($p < 0.05$).

A similar number of responses were obtained indicating strongly agree (n = 134; 27%), agree (n = 138; 27.8%) and unsure (n = 144; 29%) to the statement: “I would like my organs to be donated when I die”, with a minority of respondents disagreeing (n =35; 7.1%) and strongly disagreeing (n =45; 9.1%) ($p < 0.05$).

The response patterns for questions 51, 52 and 53 were very similar, with question 51 and 53 being almost identical. In all three of these questions, the majority of respondents selected “unsure”.

In regard to whether they had thought about their death, 181 (36.5%) respondents agreed that they had and 151 (30.4%) selected “unsure” as a response ($p < 0.05$). By contrast, 164 (33%) respondents disagreed with the statement ($p < 0.05$).

Fewer respondents ($n = 128$; 25.8%) agreed with the statement that they had thought about their funeral plans and close to 33.3% ($n = 165$) were unsure about this statement ($p < 0.05$). Most respondents ($n = 203$; 40.9%) indicated that they had not done so ($p < 0.05$).

Statement 54: “I avoid discussing death”, yielded an almost even split between “agree” ($n = 141$; 28.4%) and “disagree” ($n = 148$; 29.8%) and a lesser, but similar, split between “strongly agree” ($n = 51$; 10.3%) and “strongly disagree” ($n = 48$; 9.7%). In addition, 108 (21.8%) respondents selected “unsure” ($p < 0.05$).

An equal number of respondents ($n = 119$; 24%) selected “unsure” and “disagree” in response to the statement on whether they had thought about death more since they became emergency care providers. Fewer respondents selected “strongly agree” ($n = 58$; 11.7%) and “strongly disagree” ($n = 67$; 13.5%), with 133 (26.8%) agreeing with the statement ($p < 0.05$).

The majority of respondents ($n = 293$; 59.1%) agreed with the statement that life is too short, with 17.1% ($n = 85$) being unsure and 118 (23.7%) disagreeing ($p < 0.05$).

Most respondents ($n = 334$; 67.3%) believed that there is life after death, although 107 (21.6) were unsure and 55 (11.1%) disagreed with the statement ($p < 0.05$).

Many of the statements have means close to 3.0 (the level of uncertainty). An inspection of the frequency table indicates that approximately one-third of the respondents scored across each of the collective options of agree, unsure and disagree.

4.3.5.3 Factor Analysis of Section F

Factor analysis is a statistical technique used for data reduction. In this study, this technique was used in an attempt to represent the Likert scale items in Section F with a small number of hypothetical factors in order to reveal the relationships among and between the relationships between several of the variables being measured.

The Kaiser-Meyer-Olkin (KMO) and Bartlett's test was done to show the measure of the strength of the relationship between variables. The requirement is that the KMO measure of sampling adequacy should be greater than 0.50 and Bartlett's test of sphericity should be less than 0.05. In all instances, these conditions were satisfied, which indicated that the data was suitable for the factor analysis procedure (Table 4.25).

Table 4.25 Summarised KMO and Bartlett's test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.722
Bartlett's test of sphericity	Approx. Chi-Square	1148.561
	df	120
	Sig.	0.000

The rotated component matrix is shown in Table 4.26 below.

With reference to Table 4.26:

- Principal component analysis was used as the extraction method, and varimax with Kaiser normalisation was the rotation method applied. The latter is an orthogonal rotation method that minimises the number of variables that have high loadings on each factor, thus simplifying the interpretation of the factors.
- Factor analysis/loading indicates inter-correlations between variables.
- Items or questions that loaded similarly imply measurement along a similar factor. The content of items loading at or above 0.5 (and using the higher or highest loading in instances where items cross-loaded at greater than this value) was examined and effectively measured along the various components.

It should be noted that the variables that constitute Section F loaded along five components (sub-themes). This means that respondents identified different trends in the section. In this section, the splits are colour coded. These five components could be labelled, from 1 to 5, as Death awareness, Death anxiety, Death concept, Death avoidance and Death acceptance respectively.

Table 4.26 Rotated component matrix

	Component				
	1	2	3	4	5
The thought of death scares me	0.106	0.614	0.031	0.266	-0.124
Suicide is never the answer	-0.095	0.024	0.333	0.533	-0.345
I would like to die in my sleep	0.078	0.119	-0.146	0.710	0.192
I hate the sound of the word “death”	-0.107	0.759	0.040	0.174	-0.028
Euthanasia should be legal	0.087	0.102	-0.042	-0.016	0.753
I understand death	-0.032	-0.166	0.708	0.140	0.149
I would like to die before my friends and family	0.212	0.184	-0.007	0.621	0.098
I think death will be painful	0.092	0.427	0.456	-0.081	0.245
I would like my organs to be donated when I die	-0.167	-0.056	0.163	0.333	0.630
I have thought about my death	0.792	-0.013	0.068	0.161	0.063
I have thought about my funeral plans	0.761	0.043	0.013	0.090	-0.100
I have thought about the death of my loved ones	0.798	0.018	0.077	-0.002	0.002
I avoid discussing death	0.036	0.654	-0.192	0.014	0.123
I think about death more since I became an emergency care provider	0.443	0.468	0.187	-0.083	0.178
I feel life is too short	0.376	0.330	0.398	-0.006	0.034
I believe that there is life after death	0.183	0.009	0.655	-0.123	-0.172

Extraction method: principal component analysis; rotation method: varimax with Kaiser normalisation

a. Rotation converged in 7 iterations

These loadings are rational and reasonable. For example, the three items that fall into component one (death awareness) all share similar text, with the word “thought” being used in each. These sub-themes are consistent with findings reported in the literature and also can be seen in Wong’s Death Anxiety Scale (Gesser et al., 1988; Neimeyer, 1994)

4.3.5.4 Cross tabulations

The traditional approach to reporting a result requires a statement of statistical significance. Thus, a p-value is generated from a test statistic and a significant result is indicated with "$p < 0.05$". An independent variable in columns is typically cross-tabulated with the dependent variable in rows.

A second chi-square test was performed to determine whether there was a statistically significant relationship between the variables (rows vs columns). This test was used to test the null hypothesis, which states that there is no association between the two variables and the alternative hypothesis which indicates that there is an association. Several items were shown to have a statistically significant association when cross tabulated. This information is reported using the chi square χ^2 followed by open parenthesis, which indicates the degree of freedom (*df*) and the sample size, close parenthesis, the chi-square value test statistic, and the significance level. Some of the findings related to the aim of this study are reported below.

Cross tabulation was performed between question 27 and question 17 to explore whether having received formal instruction or training on death, dying and bereavement is related to the level of comfort respondents feel when making death notifications. The results show that a statistically significant association exists between these two variables, χ^2 (4, N = 491) = 11.17, p = .025.

Table 4.27 Level of comfort experienced when making death notifications contrasted with whether formal instruction on death and dying has been received (cross-tabulation of Q27 and Q17)

Have you received any formal instruction or training on death, dying and bereavement?		**How would you rate your comfort in making death notifications?**					
		Very comfortable	**Somewhat comfortable**	**Unsure**	**Slightly uncomfortable**	**Very uncomfortable**	**Total**
Yes	Count	32	63	19	38	23	175
	% of column total	47.1	41.4	26.0	29.9	32.4	35.6
No	Count	36	89	54	89	48	316
	% of column total	52.9	58.6	74.0	70.1	67.6	64.4
Total	Count	68	152	73	127	71	491

The chi-square test conducted on question 42 and question 27 found a highly significant association between fear of death and having received formal instruction or training on death, dying and bereavement, χ^2 (4, N = 491) = 20.99, p<.001.

Table 4. 28 Formal instruction on death, dying and bereavement contrasted with fear of death (cross-tabulation of Q42 and Q27)

The thought of death scares me		**Have you received any formal instruction or training on death, dying and bereavement?**		
		Yes	**No**	**Total**
Strongly agree	Count	9	27	36
	% of column total	5.1	8.5	7.3
Agree	Count	38	118	156
	% of column total	21.7	37.3	31.8
Unsure	Count	29	47	76
	% of column total	16.6	14.9	15.5
Disagree	Count	49	75	124
	% of column total	28.0	23.7	25.3
Strongly disagree	Count	50	49	99
	% of column total	28.6	15.5	20.2
Total	Count	175	316	491

N=491

The association between responses to the question on whether respondents have received any formal instruction or training on death, dying and bereavement (Q27) and whether they have to conduct death notifications in the field (Q16) was found to be statistically significant, χ^2 (1, N = 491) = 5.33, p = .021.

Table 4.29 Death notifications in the field contrasted with formal instruction on death and dying (cross-tabulation of Q27 and Q16)

Have you received any formal instruction or training on death, dying and bereavement?		Have you had to conduct death notifications in the field? (this is the delivery of the news of a death to someone)		
		Yes	**No**	**Total**
Yes	Count	101	74	175
	% of yes	57.7	42.3	100.0
	% of column total	40.6	30.6	35.6
	% of N	20.6	15.1	35.6
No	Count	148	168	316
	% of no	46.8	53.2	100.0
	% of column total	59.4	69.4	64.4
	% of N	30.1	34.2	64.4
Total	Count	249	242	491
	% of N	50.7	49.3	100.0

N=491

A highly significant relationship was found between the responses to question 36 and those to question 17, which explored whether the respondent had participated in a simulated death notification and the level of comfort they experienced when making death notifications respectively, χ^2 (4, N = 491) = 28.07, p < .001.

Table 4.30 Comfort making death notifications contrasted with participation in simulated death notification scenario (cross-tabulation Q36 vs Q17)

Have you participated in a simulated death notification scenario?		How would you rate your comfort in making death notifications?					
		Very comfortable	**Somewhat comfortable**	**Unsure**	**Slightly uncomfortable**	**Very uncomfortable**	**Total**
Yes	Count	21	21	4	8	12	66
	% of yes	31.8	31.8	6.1	12.1	18.2%	100.0
	% of column total	30.9	13.8	5.5	6.3	16.9%	13.4
	% of N	4.3	4.3	0.8	1.6	2.4%	13.4

➡

Table 4.30 cont’d

Have you participated in a simulated death notification scenario?		How would you rate your comfort in making death notifications?					
		Very comfortable	**Somewhat comfortable**	**Unsure**	**Slightly uncomfortable**	**Very uncomfortable**	**Total**
No	Count	47	131	69	119	59	425
	% of no	11.1	30.8	16.2	28.0	13.9%	100.0
	% of column total	69.1	86.2	94.5	93.7	83.1%	86.6
	% of N	9.6	26.7	14.1	24.2	12.0%	86.6
Total	Count	68	152	73	127	71	491
	% of N	13.8	31.0	14.9	25.9	14.5%	100.0

N=491

Responses to the comfort rating in making death notifications (Q 17) and feeling adequately prepared to deal with dead or dying patients (Q14) showed a statistically significant association, χ^2 (8, N = 491) = 18.95, p = .015.

Table 4.31 Feeling adequately prepared to deal with a dead or dying patient as opposed to level of comfort when making death notifications (cross-tabulation of Q17 and Q14)

How would you rate your comfort in making death notifications?		If yes, did you feel adequately prepared to deal with that dead or dying patient?			
		Yes	**No**	**Not applicable**	**Total**
Very comfortable	Count	57	2	9	68
	% of row	83.8	2.9	13.2	100.0
	% of column total	16.5	3.4	10.3	13.8
	% of N	11.6	0.4	1.8	13.8
Somewhat comfortable	Count	106	18	28	152
	% of row	69.7	11.8	18.4	100.0
	% of column total	30.7	30.5	32.2	31.0
	% of N	21.6	3.7	5.7	31.0

➡

Table 4.31 cont'd

How would you rate your comfort in making death notifications?		If yes, did you feel adequately prepared to deal with that dead or dying patient?			
		Yes	No	Not applicable	Total
Unsure	Count	51	9	13	73
	% of row	69.9	12.3	17.8	100.0
	% of column total	14.8	15.3	14.9	14.9
	% of N	10.4	1.8	2.6	14.9
Slightly uncomfortable	Count	92	13	22	127
	% of row	72.4	10.2	17.3	100.0
	% of column total	26.7	22.0	25.3	25.9
	% of N	18.7	2.6	4.5	25.9
Very uncomfortable	Count	39	17	15	71
	% of total	54.9	23.9	21.1	100.0
	% of column total	11.3	28.8	17.2	14.5
	% of N	7.9	3.5	3.1	14.5
Total	Count	345	59	87	491
	% of N	70.3	12.0	17.7	100.0

N=491

The number of years of clinical experience (Q 4) showed a statistically significant association with the way in which respondents ranked their comfort in making death notifications (Q17), χ^2 (12, N = 489) = 25.30, p = .013.

Table 4.32 Number of years of clinical experience as opposed to level of comfort in making death notifications (cross-tabulation of Q4 and Q17)

How would you rate your comfort in making death notifications?		How many years of clinical experience do you have?				
		≤ 5	5–10	10–15	> 15	Total
Very comfortable	Count	11	36	13	8	68
	% of row	16.2	52.9	19.1	11.8	100.0
	% of column total	16.7	19.4	8.8	9.0	13.9
	% of N	2.2	7.4	2.7	1.6	13.9

➡

Table 4.32 cont'd

How would you rate your comfort in making death notifications?		How many years of clinical experience do you have?				
		≤ 5	5–10	10–15	> 15	Total
Somewhat comfortable	Count	23	57	46	24	150
	% of row	15.3	38.0	30.7	16.0	100.0
	% of column total	34.8	30.6	31.1	27.0	30.7
	% of N	4.7	11.7	9.4	4.9	30.7
Unsure	Count	8	33	24	8	73
	% of row	11.0	45.2	32.9	11.0	100.0
	% of column total	12.1	17.7	16.2	9.0	14.9
	% of N	1.6	6.7	4.9	1.6	14.9
Slightly uncomfortable	Count	16	44	39	28	127
	% of row	12.6	34.6	30.7	22.0	100.0
	% of column total	24.2	23.7	26.4	31.5	26.0
	% of N	3.3	9.0	8.0	5.7	26.0
Very uncomfortable	Count	8	16	26	21	71
	% of total	11.3	22.5	36.6	29.6	100.0
	% of column total	12.1	8.6	17.6	23.6	14.5
	% of N	1.6	3.3	5.3	4.3	14.5
Total	Count	66	186	148	89	489
	% of N	13.5	38.0	30.3	18.2	100.0

N=489

A highly significant relationship was found between the response of emergency care providers to whether they were bothered by a work-related death or dying incident (Q 20) and whether they felt adequately prepared to deal with dead or dying patients (Q14), χ^2 (2, N = 491) = 28.70, p < .001.

Table 4.33 **Level of preparation for dealing with dead or dying patients as opposed to the effect of work-related death or dying incident (cross-tabulation of Q20 and Q14)**

Has any work-related death or dying incident ever bothered you so much that you have lost sleep, missed work, had nightmares, or had any other notable effect?		If yes, did you feel adequately prepared to deal with that dead or dying patient?			
		Yes	**No**	**Not applicable**	**Total**
Yes	Count	75	32	19	126
	% of yes	59.5	25.4	15.1	100.0
	% of column total	21.7	54.2	21.8	25.7
	% of N	15.3	6.5	3.9	25.7
No	Count	270	27	68	365
	% of no	74.0	7.4	18.6	100.0
	% of column total	78.3	45.8	78.2	74.3
	% of N	55.0	5.5	13.8	74.3
Total	Count	345	59	87	491
	% of N	70.3	12.0	17.7	100.0

N=491

Pearson’s chi-squared test found a statistically significant association between the respondents’ responses to whether they felt adequately prepared to deal with a dead or dying patient (Q14) and whether they would attend a course on death, dying and bereavement (Q40), χ^2 (4, N = 491) = 11.90, p = .018.

Table 4.34 **Level of preparation for dealing with a dead or dying patient as opposed to attending a course on death, dying and bereavement (cross-tabulation of Q14 and Q40)**

Would you attend a course on death, dying and bereavement?		If yes, did you feel adequately prepared to deal with that dead or dying patient?			
		Yes	**No**	**Not applicable**	**Total**
Yes	Count	200	39	36	275
	% of yes	72.7	14.2	13.1	100.0
	% of column total	58.0	66.1	41.4	56.0
	% of N	40.7	7.9	7.3	56.0

➡

Table 4.34 cont'd

Would you attend a course on death, dying and bereavement?		If yes, did you feel adequately prepared to deal with that dead or dying patient?			
		Yes	No	Not applicable	Total
No	Count	113	15	36	164
	% of no	68.9	9.1	22.0	100.0
	% of column total	32.8	25.4	41.4	33.4
	% of N	23.0	3.1	7.3	33.4
Unsure	Count	32	5	15	52
	% of unsure	61.5	9.6	28.8	100.0
	% of column total	9.3	8.5	17.2	10.6
	% of N	6.5	1.0	3.1	10.6
Total	Count	345	59	87	491
	% of N	70.3	12.0	17.7	100.0

N=491

A chi-square test of independence was conducted between question 25 and question 14, which subsequently showed a statistically significant association between the response to the question on the feeling of preparedness to deal with a dead or dying patient in the field and the response to whether or not the respondent knew someone who had died within the last year, χ^2 (2, N = 491) = 7.27, p = .026.

Table 4.35 Level of preparation to deal with a dead or dying patient as opposed to knowing someone who died in the past year (cross-tabulation of Q25 and Q14)

Has someone you know died within the last year?		If yes, did you feel adequately prepared to deal with that dead or dying patient?			
		Yes	No	Not applicable	Total
Yes	Count	202	44	46	292
	% of column total	58.6	74.6	52.9	59.5
No	Count	143	15	41	199
	% of column total	41.4	25.4	47.1	40.5
Total	Count	345	59	87	491

N=491

A statistically significant association was found between the response to whether any adverse effects were experienced as a result of a work-related death or dying incident

(Q 20) and the response to whether the respondents had known someone who had died within the past year (Q25), χ^2 (1, N = 491) = 5.42, p = .020.

Table 4.36 Effect of work-related death or dying incident as opposed to whether someone known to the person had died within the past year (cross-tabulation of Q25 vs Q20)

Has someone you know died within the last year?		Has any work-related death or dying incident ever bothered you so much that you have lost sleep, missed work, had nightmares, or had any other notable effect?		
		Yes	**No**	**Total**
Yes	Count	86	206	292
	% of column total	68.3	56.4	59.5
No	Count	40	159	199
	% of column total	31.7	43.6	40.5
Total	Count	126	365	491

N=491

A statistically significant association was found between responses given to the statement "I avoid discussing death" (Q54) and responses to whether respondents knew someone who had died within the last year (Q25), χ^2 (4, N = 491) = 10.53, p=.032.

Table 4.37 Knowing someone who had died within the past year as opposed to avoiding discussion of death (cross-tabulation of Q25 and Q54)

I avoid discussing death		Has someone you know died within the last year?		
		Yes	**No**	**Total**
Strongly agree	Count	24	27	51
	% of column total	8.2	13.6	10.4
Agree	Count	87	52	139
	% of column total	29.8	26.1	28.3
Unsure	Count	60	47	107
	% of column total	20.5	23.6	21.8
Disagree	Count	98	48	146
	% of column total	33.6	24.1	29.7
Strongly disagree	Count	23	25	48
	% of column total	7.9	12.6	9.8
Total	Count	292	199	491

Statistical tests found a significant association between the responses to whether respondents knew someone who had died within the last year (Q 25) and how they ranked their response to the statement "I have thought about my death" (Q 51), χ^2 (4, N = 491) = 10.72, p = .030.

Table 4.38 Knowing someone who died in the last year as opposed to thoughts of own death (cross-tabulation of Q25 and Q51)

I have thought about my death		Has someone you know died within the last year?		
		Yes	**No**	**Total**
Strongly agree	Count	29	17	46
	% of row	63.0	37.0	100.0
	% of column total	9.9	8.5	9.4
	% of N	5.9	3.5	9.4
Agree	Count	90	43	133
	% of row	67.7	32.3	100.0
	% of column total	30.8	21.6	27.1
	% of N	18.3	8.8	27.1
Unsure	Count	87	62	149
	% of row	58.4	41.6	100.0
	% of column total	29.8	31.2	30.3
	% of N	17.7	12.6	30.3
Disagree	Count	55	38	93
	% of row	59.1	40.9	100.0
	% of column total	18.8	19.1	18.9
	% of N	11.2	7.7	18.9
Strongly disagree	Count	31	39	70
	% of row	44.3	55.7	100.0
	% of column total	10.6	19.6	14.3
	% of N	6.3	7.9	14.3
Total	Count	292	199	491
	% of N	59.5	40.5	100.0

N=491

Scaled responses to the question on whether the thought of death scares the respondents (Q42) and the rating given by respondents to their levels of comfort in making death notifications (Q17) was found to have a highly significant association, χ^2 (16, N = 491) = 32.48, p = .009.

Table 4.39 Fear of death as opposed to rating of comfort level in making death notifications (cross-tabulation of Q17 and Q42)

How would you rate your comfort in making death notifications?		The thought of death scares me					
		Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Total
Very comfortable	Count	4	16	8	16	24	68
	% of row	5.9	23.5	11.8	23.5	35.3	100.0
	% of column total	11.1	10.3	10.5	12.9	24.2	13.8
	% of N	0.8	3.3	1.6	3.3	4.9	13.8
Somewhat comfortable	Count	8	41	21	50	32	152
	% of row	5.3	27.0	13.8	32.9	21.1	100.0
	% of column total	22.2	26.3	27.6	40.3	32.3	31.0
	% of N	1.6	8.4	4.3	10.2	6.5	31.0
Unsure	Count	3	24	16	17	13	73
	% of row	4.1	32.9	21.9	23.3	17.8	100.0
	% of column total	8.3	15.4	21.1	13.7	13.1	14.9
	% of N	0.6	4.9	3.3	3.5	2.6	14.9
Slightly uncomfortable	Count	11	47	19	31	19	127
	% of row	8.7	37.0	15.0	24.4	15.0	100.0
	% of column total	30.6	30.1	25.0	25.0	19.2	25.9
	% of N	2.2	9.6	3.9	6.3	3.9	25.9
Very uncomfortable	Count	10	28	12	10	11	71
	% of row	14.1	39.4	16.9	14.1	15.5	100.0
	% of column total	27.8	17.9	15.8	8.1	11.1	14.5
	% of N	2.0	5.7	2.4	2.0	2.2	14.5
Total	Count	36	156	76	124	99	491
	% of N	7.3	31.8	15.5	25.3	20.2	100.0

N=491

A statistically significant association was found between whether respondents felt adequately prepared to deal with a dead or dying patient in the field (Q14) and how they ranked their level of agreement with the statement that the thought of death scares them (Q42), χ^2 (8, N = 491) = 15.68, p=.047.

Table 4.40 Fear of death as opposed to level of preparation for dealing with dead and dying patients (cross-tabulation of Q14 and Q42)

If yes, did you feel adequately prepared to deal with that dead or dying patient?		The thought of death scares me					
		Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Total
Yes	Count	20	109	50	91	75	345
	% of yes	5.8	31.6	14.5	26.4	21.7	100.0
	% of column total	55.6	69.9	65.8	73.4	75.8	70.3
	% of N	4.1	22.2	10.2	18.5	15.3	70.3
No	Count	8	26	7	11	7	59
	% of no	13.6	44.1	11.9	18.6	11.9	100.0
	% of column total	22.2	16.7	9.2	8.9	7.1	12.0
	% of N	1.6	5.3	1.4	2.2	1.4	12.0
Not applicable	Count	8	21	19	22	17	87
	% of N/A	9.2	24.1	21.8	25.3	19.5	100.0
	% of column total	22.2	13.5	25.0	17.7	17.2	17.7
	% of N	1.6	4.3	3.9	4.5	3.5	17.7
Total	Count	36	156	76	124	99	491
	% of N	7.3	31.8	15.5	25.3	20.2	100.0

N=491

All chi-squared test results with p-values in excess of 0.05 support the null hypothesis that there is no significant relationship between those variables. In this section, some of the significant and relevant associations that were identified were presented. In the following section further correlations between items in section F of the questionnaire are explored.

4.3.5.5 Correlations

Bivariate correlations were also performed on the ordinal data, with Spearman's correlation coefficient being used for the items in Section F of the questionnaire. The use of Spearman's correlation is most appropriate for ordinal level data because these data are often not normally distributed and, thus, do not meet the requirements for the use of a Pearson correlation, which requires interval-level and normally distributed data. A positive statistically significant correlation suggests that as the value of one variable increases the value of another variable will also increase, while a negative correlation value indicates an inverse relationship. The interpretation and analysis done using Spearman's correlation determines whether a statistically significant correlation exists with a p-value at or below 0.05. In addition, it subsequently determines the direction of the correlation based on having either a positive or negative sign in the results. Finally, it interprets the strength of the correlation based on the correlation coefficient value (Brown and Coombe, 2015). All the results may be found in Appendix H. All statistically significant relationships are indicated by a * or **.

Accordingly, the results indicate the following patterns:

Spearman's correlation analysis revealed multiple positive relationships between variables and a few negative relations with varying degrees of strength of association. Section F attempted to explore the emergency care provider's attitude towards death as well as identify certain personal attributes and their association.

The analysis revealed that there was a moderate positive association between "the thought of death scares me" and "I hate the sound of the word death", $r(496) = .39$, $p < .001$. In addition, "the thought of death scares me" also showed a slight to moderate association with the statements "I would like to die before my friends and family" ($r_s = .21$, $p < .001$) and "I think about death more since I became an emergency care provider" ($r_s = .27$, $p < .0001$). A slight negative association was noted between "the thought of death scares me" and "I understand death", $r(496) = -.10$, $p < .001$, thus implying that the more one understands death, the less one will fear it.

Understanding death also had a slight to moderate positive association with "suicide is never the answer", $r(496) = .21$, $p < .001$.

The correlation test revealed a moderate positive association between "I hate the sound of the word death" and "I avoid discussing death", $r(496) = .36$, $p < .001$.

Accordingly, the more one avoids discussing death, the more one will hate the word death. A slight negative association was found between “I understand death” and “I avoid discussing death”, *r*(496) = -.14, p < .001. Hence, the more one discusses death, the more one will understand it.

“I think about death more since I became an emergency care provider”, “I feel life is too short” and “I believe that there is life after death” were all shown to have a slight to moderate positive association with the statement “I think death will be painful”, with *r*(496) = .26, .27, and . 21, p < .001, respectively.

A slight inverse association was found between the statement “I would like my organs to be donated when I die” and the statements “I have thought about my funeral” and “I have thought about the death of my loved ones”, *r*(496) = -.11, p < .001.

A moderate positive association was found between “I think about death more since I became an emergency care provider” and “I feel life is short”, *r*(496) = .32, p < .001.

4.4 CONCLUSIONS

This chapter presented the results of the descriptive statistics compiled from this research in the form of graphs, cross tabulations and other figures for the quantitative data that was collected. In addition, factor analysis and correlation test results were presented. These research findings will be discussed further in Chapter 5.

CHAPTER 5 DISCUSSION

5.1 INTRODUCTION

The aim of this study was to investigate how prepared emergency care providers are to deal with death, dying and bereavement. In this chapter, the results of the study are discussed as with a view to addressing the research aim and the objectives.

To address these research aim and objectives, the discussion will follow a similar format to chapter four, which was based on the layout of the research tool.

5.2 EXPOSURE TO DEATH, DYING AND BEREAVEMENT

In the course of their everyday duties, emergency care providers are exposed to events involving suffering and tragedy, which may result in them experiencing posttraumatic symptoms and depression (Beaton et al., 1998: 822; Clohessy and Ehlers, 1999: 251; Alexander and Klein, 2001: 76; Regehr, Goldberg and Hughes, 2002: 501; Regehr, 2005: 97; Minnie, Goodman and Wallis, 2015: 12). Cross-sectional studies have shown that approximately one-quarter to one-third of emergency care providers have trauma symptoms in the high to severe range, consistent with a diagnosis of posttraumatic stress disorder (Alexander and Klein, 2001: 78; Regehr et al., 2002: 502; Regehr, 2005: 112).

The findings of the current study are consistent with those mentioned above, as around a quarter of the respondents (n = 126; 25.4%) reported intrusive symptoms such as losing sleep, missing work, having nightmares or experiencing some significant effect in response to a work-related death or dying incident ($p<0.01$). A fifth of the affected respondents (n = 25; 20%) stated that the effects had been felt within the six months prior to them answering the questionnaire ($p<0.01$).

A significant number of respondents (n = 206; 42%) reported that the DCAS provided professional debriefing after a call involving a death, but the majority (n = 285; 58%) reported that it did not ($p<0.01$). This may imply that the availability of professional debriefing is not well known among the emergency care providers in the ambulance services, as further results revealed that only twenty respondents (4.1%) had made use of the professional counselling provided by the Dubai Corporation of Ambulance Services ($p<0.01$).

This finding corresponds with reports of suppression of symptoms, emotional reactions and avoidance in EMS personnel found in other studies (Pajonk et al., 2011: 142; Williams, 2012: 369; Minnie et al., 2015: 15). In the current research, the majority of respondents (n = 106; 84%) who reported suffering adverse effects as a result of a work-related death or dying incident had not sought any professional counselling ($p<0.01$). A possible explanation for this may be what has been referred to in the literature as "the John Wayne Syndrome", in terms of which males in the EMS profession are expected to cope with anything they are presented with (Williams, 2012: 370).

5.2.1 Personal Exposure to Death, Dying and Bereavement

A significant number of respondents (n = 292; 59.5%) reported knowing someone who had died in the past year ($p<0.01$). This included close relatives like parents, siblings, a child and a spouse. Such personal exposure to death, dying and bereavement may be considered a normal part of life that can happen to anyone at any time, but there may be implications for healthcare providers and, in particular, emergency care providers who are faced with death, dying and bereavement as part of their daily duties.

When dealing with death, dying and bereavement, healthcare providers are expected to show empathy, be available to the person in distress and show compassion while remaining sufficiently detached to enable them to function effectively in their helping role (McFarland et al., 1994: 136; Grevin, 1996: 493; Corr, Corr and Bordere , 2013: 177; Pessagno, Foote and Aponte, 2014: 208).

Empathy is a complex and multidimensional construct that involves various aspects "such as perspective taking, affect sharing, feeling concern for others and understanding another's situation" (Neumann et al., 2016: 244). One study found that emergency care providers displayed low levels of empathy as an adaptive mechanism in their "chronically stressful work environment" (Grevin, 1996: 494). Thus, caring and empathising with patients and their families can cause significant stress, which may be the result of internal factors such as "previous or current life experience, personal death experience, too much emotional investment" without sufficient replenishment over a long period of time (Renzenbrink, 2011: 203).

As a result of the emotional exhaustion caused by long-term involvement in emotionally demanding situations, emergency care providers are at risk of experiencing burnout and compassion fatigue (Maslach, Rutgers and Leiter, 1997; Van der Ploeg and Kleber, 2003: i46). This risk is increased when they also have to cope with personal loss, thus having to manage the task of keeping the personal loss and difficult emotions separate from those of their patients. This requires heightened self-awareness and self-nurturing, as well as organisational support that includes adequate leave, supervision and ongoing education and training (Renzenbrink, 2011: 203; Meagher and Balk, 2013: 407).

Nevertheless, if an individual who has suffered a personal loss has dealt with it in a constructive manner, they may be better prepared to show empathy. To do this, they must have addressed their own death anxiety and attitudes. Dying and bereaved individuals have reported that being told “I know how you feel” is not helpful and may be perceived as an attempt to trivialise or minimise their feelings (Corr et al., 2013: 176). Accordingly, much work has been done on developing helpful ways to improve the way individuals deal with death, dying and bereavement. However, emergency care providers and other healthcare workers seldom have access to these strategies and are therefore underprepared.

5.2.2 Family Exposure and Vicarious Traumatisation

The majority of respondents working in the DCAS (n=382; 77%) are males between the ages of 26 and 35, and 86.1% (n = 421) of the respondents are married ($p<0.01$). It has been found that married respondents may cope by debriefing with their spouses; however, sharing gruesome and graphic details with a spouse may result in discomfort, distress and visual imagery (Regehr, 2005: 99). Family support, and in particular the support of a spouse, has been noted as being a primary mediator for work-related stress responses, yet the family may be vulnerable to transmitted stress or distress and thus experience vicarious traumatisation (Alexander and Klein, 2001: 79 ; Regehr, 2005: 108).

While both formal and informal support structures may exist in the emergency medical services, these seldom, if ever, extend to family members who have to deal with the array of emotional responses that working in EMS may elicit (Regehr, 2005: 112). There is thus the potential for a vicious cycle to be formed when emergency care providers are underprepared to deal with their exposure to critical incident stressors like death, dying and bereavement, and subsequently adopt unhealthy coping strategies like emotional numbing which may place a strain on their relationships and families.

There have been mixed reports about the effectiveness of critical incident stress debriefing (CISD) with some studies claiming that it can cause harm (Figley, 1995; Moran, 1998; Scully, 2001: 37; Sterud, Ekeberg and Hem, 2006: 82; Pessagno et al., 2014: 209; Minnie et al., 2015: 16). Employee Assistance Programmes (EAPs) comprise a multi-layered model that uses a Peer Support Officer (PSO) to provide early support to an emergency care provider following exposure to a potentially traumatic incident and are presented as an alternative to and an improvement on CISD (Scully, 2001: 38). This model includes psychological first aid education and counselling skill development workshops, which are embedded in the workforce and which rely on collaboration between the employer, professional counsellors, trained peer support officers and "extensive education and resilience building for employees" (Scully, 2001: 40). A review of self-report, usage and archival data collected over 18 years has shown that this model offers significant benefits to employees and their family members (Scully, 2001: 42). The main difference between this model and CISD is the extensive education, collaboration with professional counsellors and skill development and training that it offers to emergency care providers.

CISD and EAPs are both reactive measures for mitigating and addressing symptoms following exposure to a critical incident stressor like death or dying. A longitudinal study conducted by Marmar et al. (1999) over three years found only modest symptom improvement after exposure to a critical incident despite traditional support like CISD. It was subsequently concluded that emergency care providers are at risk of chronic symptomatic distress.

Despite the ongoing debate, most respondents (n = 344; 70.1%) in the current study stated that counselling should be provided by the employer ($p<0.01$).

Although the family are seldom considered to be victims of work-related trauma, the findings of this study highlight the importance of providing adequate preparation to deal with death, dying and bereavement and other critical incident stressors prior to exposure and to have systems in place to monitor and provide support as needed.

Accordingly, a proactive approach is needed in order to prepare emergency care providers before they are exposed to sudden, unexpected and traumatic deaths in the prehospital setting, as well as the growing number of dying patients who require end-of-life care (Barton, 1972: 175; Dickinson, Sumner and Frederick, 1992: 281; Schmidt, Norton and Tolle, 1992: 643; Smith-Cumberland and Feldman, 2006: 89; Ponce et al., 2010: 538; Williams, 2012: 517; Douglas et al., 2013a: 152).

5.3 EDUCATION AND PROFESSIONAL TRAINING

Most of the respondents (n = 406; 84.7%) indicated that they held a Bachelor's degree in nursing and 56 (11.9%) a Bachelor's degree in EMS ($p<0.01$). Those who reported having both nursing and EMS qualifications (n = 185; 38.4%) tended to hold a Bachelor's degree in nursing with an in-service emergency medical technician – basic (EMT-B) certification ($p<0.01$). However, there are substantial differences between the respective Bachelor's curricula and, in addition, the respondents had obtained their qualifications in various countries, including India, Philippines, Jordan, Egypt, Sudan and the United Arab Emirates. Although death is a universal human experience, death education and responses to death are influenced by culture. Accordingly, the cultural diversity that occurs in death attitudes, customs and death systems may present challenges in a pluralistic society like Dubai and requires emergency care providers to develop cultural competency (Kastenbaum, 2009; Meagher and Balk, 2013: 398; Corr, 2015: 23). Culture in this context is very important as it informs the beliefs and values surrounding illness and death, the experience of pain, sharing information about dying, the interpretation of the ethical imperative of truth telling and practices around the care and disposal of the body (Koenig and Gates-Williams, 1995: 245). By becoming culturally competent, emergency care providers can gain greater understanding of and connection to people whose customs are unfamiliar (Corr, 2015: 24).

Another difference between the Bachelor of nursing and the Bachelor of EMS qualifications is the environment in which the students are being prepared to work. Nurses are generally trained to work in a controlled clinical environment as part of a multidisciplinary team which is often led by a physician. Emergency care providers, on the other hand, are trained to deal mainly with medical and trauma emergencies in unpredictable and usually uncontrolled environments, and are often required to work independently. Thus, the type of death education that is covered in these programmes is different and varies according to the death typology.

Death education for nurses is generally concerned with end-of-life care and the literature reports that this has been identified as a deficiency for nursing students and practising nurses (Murray, 1974: 1250; Leighton and Dubas, 2009: e223; Cavaye and Watts, 2014: 17). On the other hand, death education for emergency care providers emphasises the medical and technical characteristics of death with very little emphasis on death notification (Smith and Walz, 1995: 258; Smith-Cumberland, 2006: 637).

The training and education that is required for emergency care providers must be unique and should encompass the diversity of the different types of death, while focusing on the differences between hospital and prehospital settings (Smith-Cumberland, 2006: 647). Traumatic death, which is sudden, violent, inflicted, and/or intentional and shocking can be challenging for emergency care providers (Meagher and Balk, 2013: 273).

A further breakdown of the results reveals that there were far fewer (n = 66; 13.9%) advanced life support emergency care providers when those with a Bachelor's degree in EMS are combined with those with an advanced EMT certificate ($p<0.01$). Studies have shown that personnel with higher qualifications and more experience may be more reluctant to admit that they find an incident traumatic (Alexander and Klein, 2001; Minnie et al., 2015). The current study found a statistically significant association between the way in which respondents ranked their comfort in making death notifications and the number of years of clinical experience $\chi^2(12, N = 489) = 25.30$, $p=.013$. This finding may complement the findings in the studies mentioned above that found that more experienced providers are reluctant to admit to being traumatised.

Most of the respondents (n = 316; 64.4%) stated that they had not received any formal education or training on death, dying and bereavement ($p<0.01$). Over the years, death education has become a standard component of most nursing and EMS programmes and is usually integrated into the basic curriculum (Dickinson et al., 1992; Smith, Walz and Smith, 1999). The current research obtained similar results, with the respondents who reported receiving education or training on death, dying and bereavement (n = 110; 23.1%) stating that this training formed part of a section of a specific module in their studies ($p<0.01$). However, as Dickinson et al. (2007) maintain, a separate course on death education would be preferable to the integration of death education into other coursework.

Most participants who received formal instruction on death, dying and bereavement (n = 98; 46%) reported that the topic of coping with death and dying had been covered in their training ($p<0.01$). A study conducted in the USA found that death education in paramedic programmes usually covered legal-ethical issues (Smith and Walz, 1995: 64) and that most death education courses do not address death in the emergency setting (Smith and Walz, 1995: 66). This lacuna is surprising particularly because the literature has shown that death notification is particularly stressful in the emergency setting (Iserson, 2000: 75; Ponce et al., 2010: 540; Roe, 2012: 134; Hobgood et al., 2013: 207; Galbraith et al., 2014: e95). A small minority of respondents (n = 7, 1.5%) in the current study reported that death notification as a topic had been covered during their training ($p<0.01$).

A review of the literature showed that death education lacks universality and tends to address specific or narrow areas (Smith et al., 1999). The findings of the current study are consistent with this finding.

Few studies report on the educational quality of death education and it is unknown whether healthcare professionals are receiving comprehensive instruction (Smith et al., 1999). The current study found that the majority of death education and training was carried out by nursing or paramedic instructors and that most of this training lasted between an hour and a day. This comprises a very small percentage of time in a four-year bachelor’s degree programme and usually takes place during the introductory courses in the first year of the programme.

5.4 PREPARATION TO DEAL WITH DYING, DEATH AND BEREAVEMENT

Despite the quality, the short duration or the absence of death education, most respondents (n = 354; 70.3%) felt adequately prepared to deal with dead or dying patients ($p<0.01$). This is inconsistent with the literature which showed that most physicians and paramedics felt inadequately prepared to deal with death and dying in the emergency setting (Field and Howells, 1988: 9; Weeks, 1989: 17; Dyer, 1992: 1265; Schmidt et al., 1992: 643). It is also inconsistent with the responses provided to other questions in the current study.

Further results of this study reveal that the majority of respondents had not participated in any graded simulation exercises involving death, death notification, and conscious terminally ill or dying patients, and in addition, they had not had any other graded assessments on death and dying. It has been reported in the literature that emergency care providers do not receive adequate training in death and dying, which is consistent with the findings of this study (Norton et al., 1992: 235; Smith and Walz, 1995: 259). Emergency care providers are therefore left to develop their own methods for dealing with the tasks associated with death-related work such as declaring death, performing death notification, family-witnessed resuscitation and termination of resuscitation. These are regarded as stressful aspects of death-related work in the prehospital or emergency setting (Schmidt et al., 1992: 644; Ponce et al., 2010: 539; Roe, 2012: 133).

5.4.1 Field Declaration of Death

In this study we found conflicting results regarding declaration of death in the field, with the majority of respondents (n = 288; 58.7%) reporting that they were allowed to declare death in the field, in the face of a significant number of respondents (n = 203, 41%) who reported that they are not allowed to do so ($p<0.01$). Unlike conventional emergency medical services which are staffed by EMS trained personnel, the DCAS has mainly qualified nurses with Bachelor’s degrees and therefore the convention whereby skills and tasks are assigned according to level of EMS qualification does not apply. According to convention, basic life support emergency care providers have limited scope to declare death in the field, as this generally requires the criterion of obvious signs of death such as rigor mortis, decomposition and traumatic injuries that are inconsistent with life, such as decapitation or visible brain matter. Since these conventions do not exist in the DCAS, those respondents who stated that they are not allowed to declare death in the field would thus have to transport the patient to hospital to be declared dead by a physician.

5.4.2 Termination of Resuscitation and Death Notification

The study showed an almost even split between respondents regarding whether or not they had to conduct death notification in the field. This difference is significant because of the large sample size of the study. Slightly more respondents (n = 249; 50.7%) stated that they had had to conduct death notifications in the field, as opposed to respondents (n = 242; 49.3%) who stated that they have not had to do so ($p<0.01$). The implication is that a significant number of patients are being transported to hospital, perhaps with CPR in progress, in order for a physician to declare death and to avoid having to perform the death notification. This reluctance to terminate resuscitation in the field and conduct death notification may be associated with death anxiety and inadequate education and training on how to perform death notification and how to deal with the bereft (Ponce et al., 2010: 541). The responses revealed a split on the level of comfort that respondents felt about making death notifications. Some respondents (n = 73; 14.7%) were unsure about how they felt about it, while most were either somewhat comfortable or somewhat uncomfortable making death notifications ($p<0.01$). More respondents (n = 71; 14.3%) stated that they were very uncomfortable compared to those (n = 68; 13.7%) who reported being very comfortable ($p<0.01$). A statistically significant association was found between the level of comfort respondents felt when making death notifications and the receiving of formal instruction or training on death, dying and bereavement. ($\chi^2(4, N = 491) = 11.17$, $p=.025$). Responses to whether the thought of death scared respondents were also found to have a highly significant association with comfort levels in making death notifications. ($\chi^2(16, N = 491) = 32.48$, $p=.009$).

Studies conducted on the effect of death education on death anxiety in nurses and emergency care providers are consistent in showing a decrease in death anxiety after undertaking comprehensive death education programmes which include the use of simulation (Murray, 1974: 1250; Hurtig and Stewin, 1990: 30; Hobgood et al., 2005: 218; Smith-Cumberland and Feldman, 2006: 94). The current study found a highly significant relationship between whether respondents had participated in a simulated death notification and the level of comfort they experienced when making them. ($\chi^2(4, N = 491) = 28.07$, $p<.001$).

In view of the fact that 126 respondents (25.4%) reported experiencing intrusive symptoms from work-related death or dying incidents, it is evident that they were not adequately prepared to deal with this aspect of their jobs. The majority of respondents (n = 275; 55.4%) stated that they would attend a course on death, dying and bereavement, which is further evidence that they acknowledge the shortfall in their preparation to deal with death, dying and bereavement in the prehospital setting ($p<0.01$). Most respondents indicated that they would like to learn more about all the listed topics, with a significant number of respondents specifically selecting coping with death and dying, declaration of death and death notification ($p<0.01$). A highly significant relationship was found between respondents who felt adequately prepared to deal with dead or dying patients and those who had experienced intrusive symptoms as a result of work-related death or dying incidents $\chi^2(2, N = 491) = 28.70, p<.001$.

Those who stated that they would not attend a course on death, dying and bereavement might have felt that they knew enough. On the other hand, this may have been linked to the findings of this study which indicate that more than half of the respondents either hated the sound of the word “death” or were uncertain about how they felt about it.

5.5 EMERGENCY CARE PROVIDER’S ATTITUDE TOWARDS DEATH

The analysis of the Likert scale responses in Section F of the questionnaire revealed a significant difference between the ways in which respondents scored (agree, unsure, disagree) ($p<0.01$). Subsequently, five sub-themes emerged from the factor analysis and rotation, namely, death awareness, death anxiety, death concept, death avoidance and death acceptance. These themes are consistent with the themes that emerged in the literature on death attitudes and anxiety (Gesser, Wong and Reker, 1988: 127; Neimeyer, 1994: 284; Tomer and Eliason, 1996: 351). Furthermore, negative attitudes towards death such as death anxiety (n= 270; 54.4%) and death avoidance (n=300; 60.4%) were found among the emergency care providers who participated in this study ($p<0.01$).

Contrary to the popular belief that emergency care providers are fearless, the study found that a significant number of participants (n=270; 54.4%) were either scared of the thought of death or uncertain about how they felt about it ($p<0.01$). Death anxiety or “thanatophobia” is described as “negative emotional reactions in recognition of one’s own mortality” (Brady, 2015: 32). The factor analysis indicated inter-correlations between respondents who were scared by the thought of death, had thought about their own death (.79) and funeral plans (.76) as well as the death of their loved ones (.79). For many individuals, death is removed from the forefront of their minds and that contributes to a culture of death avoidance or denial (Brady, 2015: 32). Emergency care providers cannot deny or avoid the reality of death owing to their exposure as part of their work and are thus susceptible to anxiety about death (Tomer and Eliason, 1996: 343; Payne, Dean and Kalus, 1998: 702; Yalom, 2008: 216; Brady, 2015: 33). Other terms used to describe these feelings are “mortal fear” and “fear of finitude” and such fear can affect the mental and physical health of emergency care providers and their ability to deal safely, sensitively and efficiently with dead or dying patients and their families (Brady, 2015: 35).

Emergency care providers have greater exposure to death than the general public, but their knowledge and preparation to deal with it is at the same level (Adriaenssens, de Gucht and Maes, 2012: 1411). A highly significant association was found between fear of death and having received formal instruction or training on death, dying and bereavement $\chi^2(4, N = 491) = 20.99, p<.001$.

Further factor analysis showed that respondents who hated the sound of the word death avoided discussing it (.65), but had thought about death more since they became emergency care providers (.46) ($p<0.01$). A slight to moderate positive association was shown between “I think about death more since I became an emergency care provider”, “I would like to die before my friends and family” (.16) and “the thought of death scares me” (.27), while a slight negative association was noted between understanding death and being scared of the thought of dying (-.10) ($P<0.01$). Understanding death is associated with neutral death acceptance, which acknowledges that death is a part of life and thus should be neither feared nor welcomed (Neimeyer, Wittkowski and Moser, 2004: 315).

The findings of this study show a consistently strong link between death education, preparation and a reduction in the adverse effects associated with death, dying and bereavement. Speaking openly about death and learning about its various aspects can facilitate positive attitudes that can be used to deal effectively with dying patients, to cope better with the death and to decrease the trauma of sudden death and the number of abnormal grief reactions for the bereft using compassionate words and actions (Smith et al., 2009).

Emergency care providers can decrease the emotional toll on themselves by gaining knowledge and developing specialised skills to be better prepared to deal with death, dying and bereavement (Smith et al., 2009). Studies have shown that death anxiety is not a “fixed entity” and the emergency care provider’s attitude towards death, dying and bereavement can be changed through interventions such as comprehensive death education, professional counselling and support (Murray, 1974: 1250; McFarland et al., 1994: 138; Smith-Cumberland and Feldman, 2006: 94; Claxton-Oldfield, Crain and Claxton-Oldfield, 2007; Douglas et al., 2013b: 159). The benefits of such preparedness extend to the emergency care provider’s family, the dying patients and the bereft.

5.6 CONCLUSION

This chapter provided a detailed explanation and discussion of the study results in relation to the research aim and objectives described both in chapter one and at the beginning of this chapter. The following chapter concludes the study.

CHAPTER 6: CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

6.1 CONCLUSION

The findings of this study have shown that emergency care providers are generally underprepared to deal with death, dying and bereavement in the prehospital setting. An investigation into the educational and professional preparation of emergency care providers with regard to death, dying and bereavement found that neither the tertiary nor the vocational education and training that respondents had received had adequately addressed the specific death-related tasks that are needed in the prehospital and emergency setting.

Thanatology, the scientific study of death and the practices related to it, has made considerable contributions to the body of knowledge that addresses the vast range of areas related to the human experience of death, dying and bereavement. Nevertheless, the current study found that these contributions have not yet made an impact on the emergency care provider’s education, training or preparation. It is reported that only a limited death education component is embedded in educational and professional offerings and is usually taught by nurses and paramedics who use didactic methods of instruction. Hannelore Wass, who is regarded as the doyen of death education, notes that this type of educational offering provides “little opportunity for participants to become knowledgeable about death and grief, to deal with their own feelings, or to develop empathy” (Wass, 2004: 295).

A review of the emergency care provider’s attitude towards death, dying and bereavement found that a number of respondents have negative attitudes towards death and reported discomfort and anxiety when dealing with death, dying patients and bereft families. This is linked to a limited exposure to death education that takes personal dimensions into account. Wass (2004) points out that the personal dimension component is intended to help students address their anxieties and become comfortable interacting with people in crisis, as well as to develop empathy (Wass, 2004: 298). Death education should go beyond the transfer of knowledge to include a holistic approach that takes the psychosocial and personal aspects into account (Wass, 2004: 298).

The investigation into the personal attributes of the emergency care provider that contribute to their preparedness to manage death, dying and bereavement in the prehospital setting yielded atypical results. Emergency care providers are generally expected to possess the ability to remain calm during stressful situations, communicate effectively, have good interpersonal skills, think critically and solve problems. However, the current study revealed that respondents were uncomfortable with certain death-related tasks such as the declaration of death, death notification and communicating with dying patients and bereft families. This discomfort is seen as a predictor of a personal fear of death and suggests that emergency care providers with high levels of death anxiety are vulnerable to adverse stress-related symptoms (Neimeyer, 1994: 284; Wass, 2004: 296).

6.2 RECOMMENDATIONS FOR IMPLEMENTATION

The following recommendation for implementation consequently stems from the results of this study.

Specialised Death Education Programme

The current study recommends that a separate comprehensive death education programme be implemented that encompasses the diversity of death and the unique challenges that the emergency and prehospital setting presents. This has already been recommended in the literature and is reiterated by the current study (Smith and Walz, 1995: 267; Wass, 2004: 297; Dickinson et al., 2007: 289).

A comprehensive death education programme for emergency care providers should include lectures, discussions, small-group exercises, role-play and workbook exercises (Smith, 2006: 638). In addition, such a programme/course should address self-care boundaries with the intention of protecting the emergency care provider from experiencing compassion fatigue and burnout and attempting to change death-related attitudes and behaviours (Meagher and Balk, 2013: 407; Smith, 2006: 643). Further, aspects of death across all age groups, end-of-life decision making, loss, grief and mourning should be covered in order to develop clinical competencies to manage these situations (Meagher and Balk, 2013: 408). Such competencies include communication skills, death notification skills and an understanding of patients' rights. Traumatic and unexpected deaths in particular require appropriate training in order for emergency care providers to give a professional response in these difficult situations.

Training is also important in helping to prevent the emergency care provider from experiencing vicarious traumatisation (Smith, 2006: 637).

Death competence is defined as the specialised skill relating to tolerating and managing individuals’ problems in regard to dying, death and bereavement and is regarded as an ethical imperative (Gamino and Ritter, 2012: 23). This ethical imperative should be brought to the forefront of emergency care provider educational programmes in order to improve the standard of care and to better prepare them to deal with death, dying and bereavement in the prehospital setting. Emergency care providers and their families, as well as the patient population and their families that they serve, may benefit from the implementation of such programmes.

6.3 LIMITATIONS TO THE STUDY

One of the limitations identified for the current study is that it did not include a qualitative component. This could have provided a deeper understanding of the underlying reasons, opinions and motivations for some of the responses to the questionnaire. The topic of death, dying and bereavement is one that individuals experience differently and, thus, an exploration of the various perspectives may have provided useful data.

Furthermore, the respondents in this study mainly comprised nurses who worked in the prehospital emergency medical services setting. This is a unique situation and may have influenced the results of the study somewhat. The consolation is that they work in the prehospital and emergency setting, and both the results and the literature show no substantial difference between the preparedness of emergency nurses and emergency care providers to deal with death, dying and bereavement in the prehospital setting.

6.4 RECOMMENDATION FOR FUTURE RESEARCH

The emergency care profession has expanded its scope of practice to address the needs of the community. Accordingly, the current study highlighted the need for end-of-life care and palliative care in the prehospital setting.

Emergency medical services are traditionally regarded as a transport service but there have already been advances in community-based ambulance programmes that provide on-scene treatment, discharge and follow-up services. Consequently, there is an opportunity to explore the way in which specially trained emergency care providers could contribute to the field of end-of-life and palliative care in the prehospital setting in order to contribute to more people experiencing a “good death” in the comfort of their homes, surrounded by friends and family.

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Appendix A – Letter of information

LETTER OF INFORMATION

Title of the Research Study:

Preparedness of emergency care providers to deal with death, dying and bereavement in the prehospital setting.

Principal Investigator/s/researcher:

Mr. Reon Conning, B.Tech:

Emergency Medical Care

Co-Investigator/s/supervisor/s:

Mr. Raveen Naidoo

(MSc. Cardiology, MSc. Medicine)

Prof R Bhagwan

(PhD. Community & Development)

Dr. Sami Ahmad

(MBBS, Clinical Doctor in Community Medicine)

Brief Introduction and Purpose of the Study:

Emergency care providers are exposed to death, dying and bereavement as part of their job. Prehospital emergency care providers have to carry out resuscitation on patients without spontaneous circulation, declare death, deliver death notifications, carry out standard operating procedures to deal with the corpse, interact with a patient who is terminally ill and dying, or just witness the reactions of families to the loss of their loved one. The manner in which an emergency care provider deals with this aspect of his job can impact the grieving process of the bereaved and the exposure to death, dying and bereavement can have an impact on the emergency care provider. Dealing with death, dying and bereavement is a complex process that requires training and education, psychological resilience, strategies for self-care and timely support. Emergency care providers need to be prepared to deal with this important aspect of their job, but little is known about their preparedness.

The purpose of this study is to assess how prepared emergency care providers are to deal with death, dying and bereavement in order to develop strategies that will help them to do this in the prehospital setting.

Outline of the Procedures:

Once you have read through this letter of information and are satisfied with its content you will be required to complete and sign a consent form.

You will then be asked to complete a short anonymous online survey which should take 5-7 minutes of your time. This is done completely voluntarily and you can withdraw your participation at any time.

The information will be collected and the researcher will analyze the data with the assistance of the supervisors and a statistician (Annexure D). Approximately 280 participants are expected to participate in the study.

The results will be reported in the final research dissertation and will be made available.

Your participation will be greatly appreciated and will make a valuable contribution to the profession of prehospital emergency medical care.

Risks or Discomforts to the Participant: None

Benefits:

This information is imperative because it may facilitate future changes in emergency care education and training and ultimately empower the emergency care provider to better deal with bereaved loved ones and also their own stresses related to dealing with death and dying.

Reason/s why the Participant May Be Withdrawn from the Study:

Participation in this study is voluntary. If you decide to participate in this study after reading this information letter, you will be given a consent form to complete. If you choose not to participate in this study, this will not negatively affect your professional career or employment. All responses will be collected anonymously. Respondents will therefore not be personally identifiable. To ensure accuracy, questionnaires (as identifiable by the unique code) that are not submitted or submitted but not fully completed will be withdrawn from the study.

Remuneration: No remuneration will be offered or provided to any participant in this study.

Costs of the Study: You will not be asked to cover any of the costs associated with this study.

Confidentiality:

If you agree to participate in this study, your input will be remain anonymous. No name or identifying details will be required to ensure that your answers are confidential and anonymous. Data will only be accessible to the primary researcher and the research supervisors.

Research-related Injury: Not applicable

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher Reon Conning (+971566902685), my supervisor Mr. Raveen Naidoo (+27813245555) or the Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Director: Research and Postgraduate Support, Prof S Moyo on 031 373 2577 or moyos@dut.ac.za

Annexure B – Consent to participate

CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Reon Conning, about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: ____,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

______________________	___________	_______	________________
Full Name of Participant	**Date**	**Time**	**Signature**

I, Reon Conning, herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher	**Date**	**Signature**
Full Name of Witness (If applicable)	**Date**	**Signature**
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Annexure C – Questionnaire

DUT DURBAN UNIVERSITY OF TECHNOLOGY

PREPAREDNESS OF EMERGENCY CARE PROVIDERS TO DEAL WITH DEATH, DYING AND BEREAVEMENT IN THE PREHOSPITAL SETTING

Thank you for agreeing to take part in this survey to investigate the preparedness of emergency care providers to deal with death, dying and bereavement. Your input in this study is very valuable and will contribute to the body of knowledge in the emergency care profession. Your participation is entirely voluntary, and you may refuse to complete any part or all of this survey. It should take you around 10 minutes to complete the survey. The information that we receive will remain completely confidential. You may withdraw your data at any time, including when the questionnaire has been submitted. If you have any questions or concerns about your rights as a participant in this survey you may contact the researcher Reon Conning on +971566902685 or rconning@hct.ac.ae to discuss them. If you find that any questions in the survey causes distress please feel free to utilize the anonymous and free services of a qualified counsellor, Dr. Nafees Saltana on +9712 206 4558 or snafees@hct.ac.ae

To fill in this questionnaire, please carefully read the statements and tick the appropriate box or boxes.

SECTION A: DEMOGRAPHIC DETAILS

1. How old are you?

≤ 25		26-35		36- 45		≥45	

2. Gender :

Male		Female	

3. Marital Status

Married		Single		Divorced		Widowed	

4. How many years of clinical experience do you have?

≤ 5 years		5 – 10 years		10 -15 years		≥ 15 years	

SECTION B: EDUCATION AND PROFESSIONAL TRAINING

5. How long ago did you obtain your first clinical qualification?

≤ 5 years		5 – 10 years		10 -15 years		≥ 15 years	

6. What type of clinical qualification do you hold?

Nursing		Emergency Medical Services		Both	

Specify Other	

7. For Nursing, tick the qualifications that you hold

Nursing Certificate		Associate Degree		Diploma	

Higher Diploma		Bachelor Degree		Post Graduate	

Other Specify		Not Applicable	

8. For Emergency Medical Services, tick the qualifications that you hold

Basic EMT Certificate		Int. EMT Certificate		Adv. EMT Certificate	

Associate Degree		Diploma		Higher Diploma	

Bachelor Degree		Post Graduate	

Other Specify		Not Applicable	

9. If you have specified other clinical qualification in question 6, please list the qualifications in space below.

SECTION C: EXPOSURE TO DEATH, DYING AND BEREAVEMENT IN THE WORKPLACE

10. Where do you currently work within Dubai Corporation for Ambulance Services?

Emergency Response Ambulance		First Responder Units		Medical Intensive Care Unit	

Helicopter Emergency Medical Services		Neonatal and Paediatric Unit		Disaster Response Team	

Doctor Response Unit		Desert Responder Unit		Motorcycle Responder	

Other Specify	

11. What is the average number of calls you attend in a shift?

< 5		5 - 10		11 -15		>15	

12. How many of these calls involve a death?

<2		2-5		5-10		10 -15		>15	

13. Can you recall your first emergency response that involved a dead or dying patient?

Yes		No	

14. If yes, did you feel adequately prepared to deal with that dead or dying patient?

Yes		No		Not Applicable	

15. Are you allowed to declare death in the field? (***this refers to the legal declaration that a person is dead***)

Yes		No	

16. Have you had to conduct death notifications in the field? (***this is the delivery of the news of a death to someone***)

Yes		No	

17. How would you rate your comfort in making death notifications?

Very Comfortable		Somewhat Comfortable		Unsure	

Slightly Uncomfortable		Very Uncomfortable	

18. Do you have a protocol, guide or procedure to follow when dealing with death in the field?

Yes		No	

19. Does the service provide professional debriefing after a call involving a death?

Yes		No	

20. Has any work related death or dying incident ever bothered you so much that you have lost sleep, missed work, had nightmares, or had any other notable affect?

Yes		No	

21. If yes, was it in the last 6 months?

Yes		No		Not Applicable	

22. Did you receive professional counselling?

Yes		No		Not Applicable	

23. If yes, was this counselling provided by your employer?

Yes		No		Not Applicable	

24. If no, do you think this service should be provided by your employer

Yes		No		Not Applicable	

SECTION D: PERSONAL EXPOSURE TO DEATH, DYING AND BEREAVEMENT

25. Has someone you know died within the last year?

Yes		No	

26. If yes, was it a/an:

Parent		Sibling		Spouse		Cousin	

Grand parent		Aunt/ Uncle		Friend		Colleague	

Other		Specify	

Not applicable	

SECTION E: DEATH EDUCATION

27. Have you received any formal instruction or training on death, dying and bereavement?

Yes		No	

28. If yes, how much time was spent on these topics?

≤ 1 hr.		1 hr. - ≤ 1 day		1 – 2 days		2 – 5 days		≥ 5 days	

Specify if > 5 days		Not Applicable	

29. Where did this instruction or training take place?

A specific module in a section of your studies		A Seminar		Work Placed Learning	

Conference/ Workshop		A Course	

Other Specify		Not applicable	

30. What topics were covered in this training?

Coping with Death & Dying		End of Life Decision Making		Loss, Grief and Mourning	

Assessment & Intervention		Death Notification		Declaration of Death	

Dealing with a Grieving child		Critical Incident Debriefing		Death Documentation	

Other Specify		Not applicable	

31. Who delivered the instruction or training on death and dying?

Nursing Instructor		Paramedic Instructor	

Social Worker		Grief Counsellor	

Specialist in Death and Dying		Psychologist	

Other Specify		Not Applicable	

32. Have you participated in a simulated death scenario?

Yes		No	

33. If yes, was this a graded simulation exercise?

Yes		No		Not Applicable	

34. Have you participated in a simulation scenario involving a conscious terminally ill or dying patient?

Yes		No	

35. If yes, was this a graded simulation exercise?

Yes		No		Not Applicable	

36. Have you participated in a simulated death notification scenario?

Yes		No	

37. If yes, was this a graded simulation exercise?

Yes		No		Not Applicable	

38. Were you required to undertake any other graded assessments on death and dying during your studies?

Yes		No		Not Applicable	

39. If yes, please specify

40. Would you attend a course on death, dying and bereavement?

Yes		No		Unsure	

41. What would you like to learn more about? (you can tick more than one response)

Coping with Death & Dying		End of Life Decision Making		Loss, Grief and Mourning	

Assessment & Intervention		Death Notification		Declaration of Death	

Dealing with a Grieving child		Critical Incident Debriefing		Death Documentation	

All of The Above	

Other Specify	

SECTION F: DEATH ATTITUDE

Please read the following statements carefully and tick the box you feel suits you best.

42. The thought of death scares me

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

43. Suicide is never the answer

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

44. I would like to die in my sleep

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

45. I hate the sound of the word “death”

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

46. Euthanasia should be legal

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

47. I understand death

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

48. I would like to die before my friends and family

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

49. I think death will be painful

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

50. I would like my organs to be donated when I die

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

51. I have thought about my death

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

52. I have thought about my funeral plans

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

53. I have thought about the death of my loved ones

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

54. I avoid discussing death

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

55. I think about death more since I became an emergency care provider

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

56. I feel life is too short

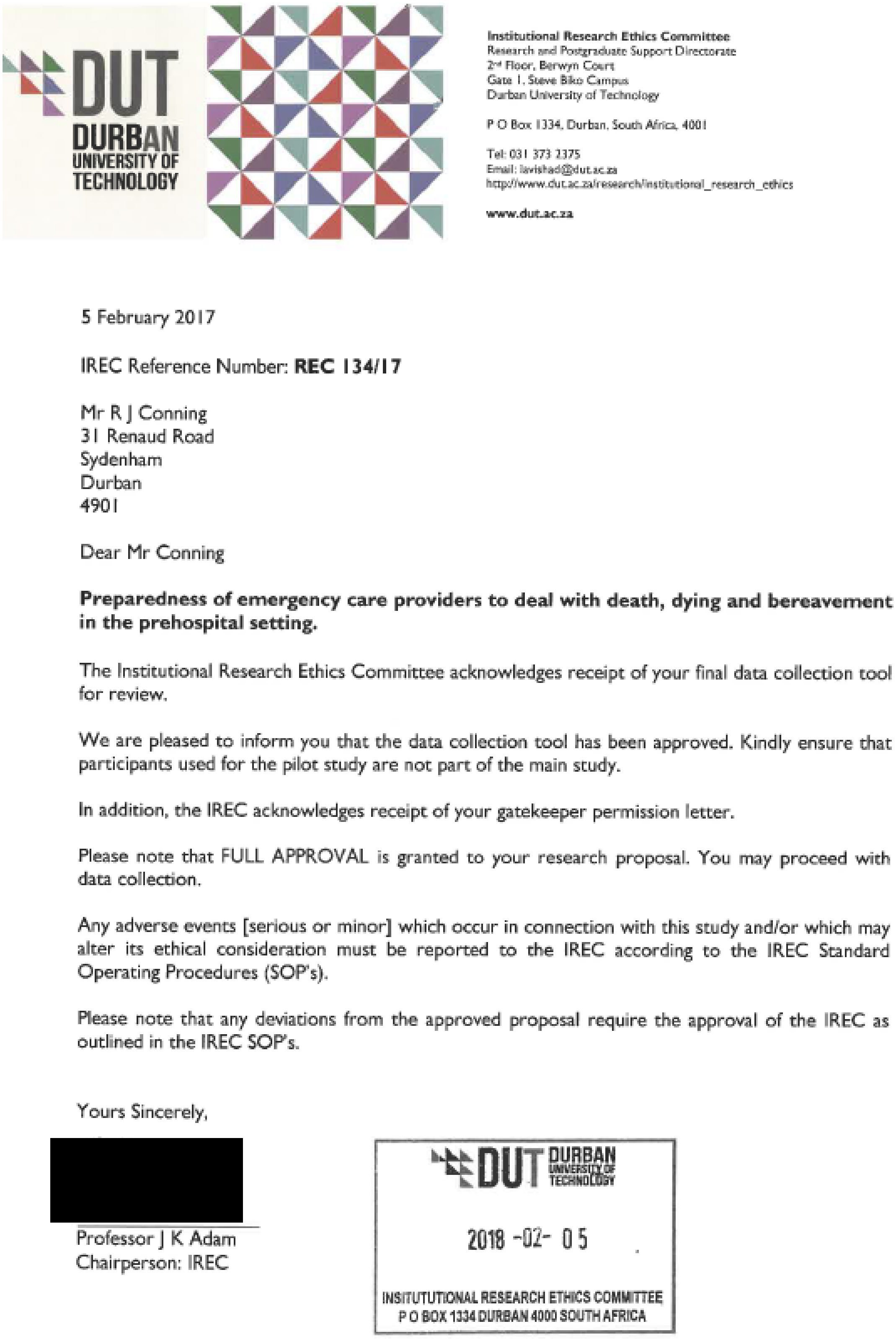
Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

57. I believe that there is life after death?

Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	

THANK YOU ONCE AGAIN FOR YOUR PARTICIPATION IN THIS STUDY. THE RESULTS OF THE STUDY WILL BE MADE AVAILABLE TO YOU ONCE PUBLISHED.

Annexure D – Full ethics approval



DURBAN
UNIVERSITY OF
TECHNOLOGY

Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

5 February 2017

IREC Reference Number: **REC 134/17**

Mr R J Conning
31 Renaud Road
Sydenham
Durban
4901

Dear Mr Conning

Preparedness of emergency care providers to deal with death, dying and bereavement in the prehospital setting.

The Institutional Research Ethics Committee acknowledges receipt of your final data collection tool for review.

We are pleased to inform you that the data collection tool has been approved. Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the IREC acknowledges receipt of your gatekeeper permission letter.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC Standard Operating Procedures (SOP's).

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely,

[redacted]

Professor J K Adam
Chairperson: IREC

DUT DURBAN UNIVERSITY OF TECHNOLOGY
2018 -02- 05
INSITUTUTIONAL RESEARCH ETHICS COMMITTEE
P O BOX 1334 DURBAN 4000 SOUTH AFRICA

Annexure E – DCAS request letter

Date: 17 December 2017

To: **His Excellency Khalifa Bin Darai**

CHIEF EXECUTIVE OFFICER: DUBAI CORPORATION OF AMBULANCE SERVICES

SUBJECT: REQUEST FOR APPROVAL TO UNDERTAKE RESEARCH

I am currently registered at Durban University of Technology through the Department of Emergency Care and Rescue with the aim of completing a Master's Degree: Emergency Medical Care in 2017. I wish to undertake a research project within Dubai Corporation of Ambulance Services.

Student Name : Reon Conning

Student no : 19801041

Supervisor : Mr. R Naidoo Contact no: +2781 324 5555

Co-Supervisors : Prof R Bhagwan Contact no: +2731 360 1281

Dr Sami Ahmad Contact no: +97150 252 0007

Title of Research:

Preparedness of emergency care providers to deal with death, dying and bereavement in the prehospital setting.

Aim of Research:

To investigate how prepared emergency care providers are to deal with death, dying and bereavement and to develop strategies that will enable providers to cope with this sensitively and efficiently in the prehospital environment.

Benefits of Research:

This information is imperative because it may facilitate future changes in emergency care education and training and ultimately empower the emergency care provider to better deal with bereaved loved ones and also their own stresses related to dealing with death and dying.A bound hard copy of the research proposal will be forwarded to your office once approval has been received from the faculty research committee of the Durban University of Technology. All data will be handled with the strictest confidentiality and only the researcher and supervisors will have access to the data. All research findings will be made available to you, in an encrypted report.

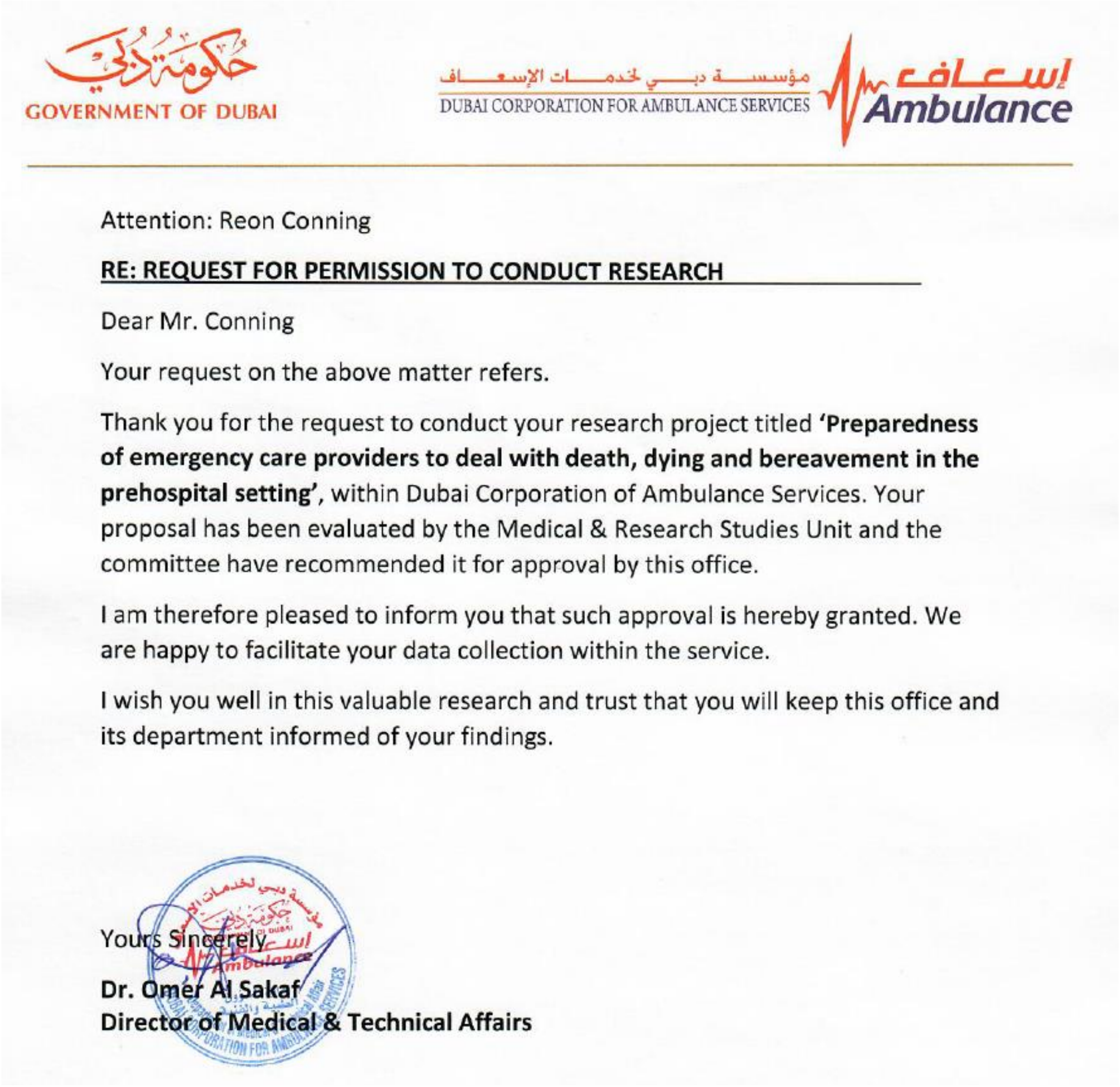
I therefore request permission to conduct a survey amongst the operational medics at DCAS. I trust this will meet your favourable consideration and approval.

Yours Sincerely

[redacted]

Reon Conning

Annexure F – DCAS approval



حكومة دبي
GOVERNMENT OF DUBAI

مؤسسة دبي لخدمات الإسعاف
DUBAI CORPORATION FOR AMBULANCE SERVICES

إسعاف
Ambulance

Attention: Reon Conning

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

Dear Mr. Conning

Your request on the above matter refers.

Thank you for the request to conduct your research project titled **'Preparedness of emergency care providers to deal with death, dying and bereavement in the prehospital setting'**, within Dubai Corporation of Ambulance Services. Your proposal has been evaluated by the Medical & Research Studies Unit and the committee have recommended it for approval by this office.

I am therefore pleased to inform you that such approval is hereby granted. We are happy to facilitate your data collection within the service.

I wish you well in this valuable research and trust that you will keep this office and its department informed of your findings.

Yours Sincerely

Dr. Omer Al Sakaf
Director of Medical & Technical Affairs

Annexure G – Pilot study report

Pilot Study Report for Data Collection Tool

Preparedness of Emergency Care Providers to Deal with Death, Dying and Bereavement in the Prehospital Setting

IREC Reference Number: **REC 134/17**

Ethical Clearance Number: **IREC 118/17**

Durban Institute of Technology

Date: 2018-01-26

Reon Johnathan Conning

Table of Contents

Introduction

The aim of this pilot study was to examine the data collection tool that will be used for the main data collection. Thabane et.al (2010) states that a pilot study is synonymous with a feasibility study, while Grimm (2010) points out that it is useful to ‘detect any problem with the questionnaire design which may lead to ambiguity of words, misinterpretation of questions, inability to answer a question, sensitive questions, and many other problems associated with the questionnaire’. Pilot testing can also test the process of administering the survey, but this was not the purpose of this pilot as I intend to distribute the main survey electronically, while the pilot was conducted manually.

This report documents the general observations and findings of the pilot study and lists all the amendments that have been made to the data collection tool in the below revision log.

Methodology

The questionnaire was printed out and delivered to one of the clinical instructors at National Ambulance Service in Abu Dhabi. A soft copy was also emailed to him in case he needed to print more. He handed the questionnaire to a field shift supervisor who administered the questionnaire during 4 different shift changes. He handed the questionnaire to whoever was available and waited for them to complete the survey and return it. 25 surveys were completed and returned in this way. The survey administrator was also questioned regarding non-verbal behaviour of participants while they completed the survey and the time taken to complete the survey.

I also asked 5 emergency care providers with more than 15 years of experience each to complete the survey and provide feedback on the data collection tool. A total of 30 questionnaires were reviewed in this pilot study and discussions were held with the 5 experienced emergency care providers.

The data collected in the pilot study will not be included in the main study and none the participants in the pilot study will be involved in the main study.

General Overview

The survey was well received and the responses to the pilot study exceeded my expectations. The pilot survey succeeded in bringing several important errors to light and raised some other important matters which will be discussed in greater detail below. These errors and important matters range from simple formatting and number anomalies and redundant words to missing response options and word changes.

The questionnaire was completed by 23 males and 7 females.

Summary of Findings and Comments

- The first observation that was noted is that it took most respondents longer than the predicted 5 to 7 minutes to complete the survey. All respondents were able to complete the survey in closer to 10 minutes. This was reported by the shift supervisor who oversaw the completion of 25 surveys and was further confirmed by the experienced emergency care providers.
- One of the experienced emergency care providers pointed out that the spacing between the words in the introduction to the survey was small and made it difficult to read.
- The word “ago” should be removed from questions 4 and 5.
- The wording of Question 5 was recommended to be changed to “How long ago did you obtain your first qualification?”
- The words “or both” should be removed from Questions 7 & 8 and the word “If” should be replaced by the word “For” in both of these questions.
- Question 7 & 8 should have a “not applicable” option
- Question 10 asks the respondents where they work in the Dubai Corporation of Ambulance Services. None of the participants in the pilot study work for DCAS,

but most either wrote National Ambulance on the paper or answered the question. Only 6 respondents left this answer blank.

- All respondents answered questions 11 and 12, despite them being linked to question 10.
- Question 11 takes time to answer as respondents have to try to calculate how many calls they may do in a month. The majority of respondents marked 20-40 calls a month. This is very low. The average number of shifts a month is between 14 and 16. That means that they are suggesting that they only do around 2 calls per shift which is far less than what is reported by the shift manager and the dispatch centre. When asked how many calls they do in an average shift, most said between 5 and 10 calls, so their answer to question 11 is not accurate. Only 2 respondents gave a more accurate response of >60 calls a month which is around 5 calls per day.
- Question 30 was missing a “not applicable” option.
- Many respondents marked most or all of the options for Question 41, so should consider adding an “all of the above” option.
- 3 respondents circled their answers instead of checking in the boxes. This is because the pilot test was paper based. The online survey will prevent this.
- Considered one response that selected “other” for Question 41. The respondent added a topic they would like to learn about, but it was listed in the options.

Omitted Answers

- Question 10 was omitted by 6 respondents as it referred to Dubai Corporation of Ambulance Services and all participants in the pilot study are National Ambulance employees
- At least 2 respondents cited religious convictions as a reason for them not knowing how to answer some of the questions pertaining to death attitude. Question 47 was a common omission between these 2 respondents and the one respondent did not know how to respond to question 48, 49, 50 & 56.

- Many respondents did not mark the “not applicable’ options. They had marked no in the preceding question, so the obvious response to the subsequent question would be “not applicable”, but many left that blank.
- One respondent answered ‘yes’ to question 38 and question 39 says: “if yes, please specify”. This respondent left this out, but it may be an oversight since it was only one person who made this omission.
- One respondent left Question 44 blank. This may have been an oversight or intentional.
- Two respondents left Question 17 blank. The question asked them to rate their comfort in making death notifications. This may have been an oversight as the option for “unsure” is available.

Limitations

The pilot study was conducted using convenience sampling and was paper based so it did not test the intended process of administering the online survey and randomized sampling.

The feedback from the shift supervisor about the non-verbal behaviours of the respondents while taking the survey is subjective. He pointed out that they all took longer than the estimated time to complete the questionnaire and that there were no obvious signs of confusion or frustration while answering the questions.

Revision Log

Question	Pilot Study Findings & Comments	Amendments made to Data Collection Tool
Introduction	• Line spacing was small and made the introduction difficult to read • Increase the estimated time to complete the survey	• Increased line spacing from 1 to 1.5 • Changed from "between 5 and 7 minutes" to "around 10 minutes"
4	The word "ago" should not be there.	Removed the word "ago"
5	• Wording should be changed to match the options provided. Instead of asking "when", should ask "How long ago" • The word "ago" should not be there	• Changed the wording in the question from "When did you obtain your first clinical qualification?" to "How long ago did you obtain your first clinical qualification?" • Removed the word "ago"
7	• The word "If" should be changed to "for" • "or both" should be removed • "nursing" does not need to be stated twice • Missing answer option – "Not Applicable"	• Replaced "if" with "For" • "or both" was removed • 2nd "nursing" was removed, so the question now reads: "For Nursing tick the qualifications that you hold" • Added answer option - "Not Applicable"
8	• The word "If" should be changed to "for" • "or both" should be removed • "EMS" does not need to be stated. • Missing answer option – "Not Applicable	• Replaced "if" with "For" • "or both" was removed • "EMS" was removed, so the question now reads: "For Emergency Medical Services tick the qualifications that you hold" • Added answer option - "Not Applicable"

Question	Pilot Study Findings & Comments	Amendments made to Data Collection Tool
11	Most respondents did not calculate the average number of calls that they did in a month, they just ticked 20-40, but when asked how many they did in a day, they stated 5-10, which would make the monthly tally much higher.	• Changed the question to ask the '…average number of calls you attend in a shift" • Changed the range options to <5, 5-10,11-15, >15
30	Missing Answer Option – " Not Applicable"	Added answer option – "Not Applicable"
41	Missing Answer Option – "All of the Above"	Added answer option – "All of the Above"

Conclusion

The pilot study provided valuable input that has allowed refinement of the data collection tool and has established the feasibility of the tool. Some responses also highlighted some interesting points for further exploration and discussion in the parent study.

References

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., Robson, R., Thabane, M., Giangregorio, Goldsmith, C. H. 2010. A tutorial on pilot studies: the what, why and how. *BMC Medical Research Methodology*, *10*, 1

Grimm, P. 2010. Pretesting a Questionnaire. *Wiley International Encyclopedia of Marketing*. 2. DOI: 10.1002/9781444316568.wiem02051

Student Number : **19801041**

Reon Conning

Signed: _ [redacted]_____ **Date:** _30 Jan 2018_

(Student)

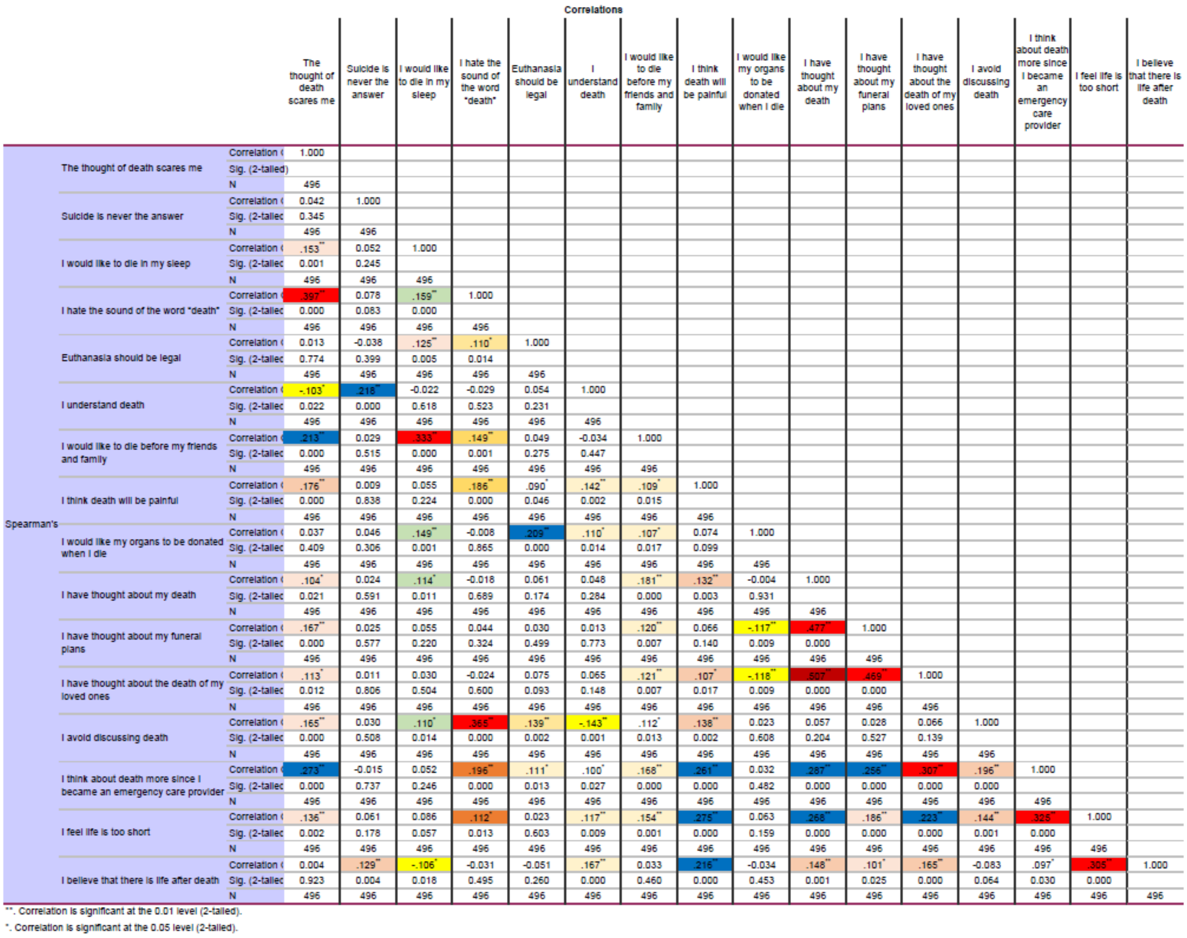
Supervisor

Mr. Raveen Naidoo

Signed: __[redacted]_____ **Date:** _30 Jan 2018

(Supervisor)

Annexure H – Correlations



Correlations

			The thought of death scares me	Suicide is never the answer	I would like to die in my sleep	I hate the sound of the word "death"	Euthanasia should be legal	I understand death	I would like to die before my friends and family	I think death will be painful	I would like my organs to be donated when I die	I have thought about my death	I have thought about my funeral plans	I have thought about the death of my loved ones	I avoid discussing death	I think about death more since I became an emergency care provider	I feel life is too short	I believe that there is life after death
Spearman's	The thought of death scares me	Correlation	1.000															
		Sig. (2-tailed)																
		N	496															
	Suicide is never the answer	Correlation	0.042	1.000														
		Sig. (2-taile	0.345															
		N	496	496														
	I would like to die in my sleep	Correlation	.153**	0.052	1.000													
		Sig. (2-taile	0.001	0.245														
		N	496	496	496													
	I hate the sound of the word "death"	Correlation	.397**	0.078	.159**	1.000												
		Sig. (2-taile	0.000	0.083	0.000													
		N	496	496	496	496												
	Euthanasia should be legal	Correlation	0.013	-0.038	.125**	.110*	1.000											
		Sig. (2-taile	0.774	0.399	0.005	0.014												
		N	496	496	496	496	496											
	I understand death	Correlation	-.103*	.218**	-0.022	-0.029	0.054	1.000										
		Sig. (2-taile	0.022	0.000	0.618	0.523	0.231											
		N	496	496	496	496	496	496										
	I would like to die before my friends and family	Correlation	.213**	0.029	.333**	.149**	0.049	-0.034	1.000									
		Sig. (2-taile	0.000	0.515	0.000	0.001	0.275	0.447										
		N	496	496	496	496	496	496	496									
	I think death will be painful	Correlation	.176**	0.009	0.055	.186**	.090*	.142**	.109*	1.000								
		Sig. (2-taile	0.000	0.838	0.224	0.000	0.046	0.002	0.015									
		N	496	496	496	496	496	496	496	496								
	I would like my organs to be donated when I die	Correlation	0.037	0.046	.149**	-0.008	.209**	.110*	.107*	0.074	1.000							
		Sig. (2-taile	0.409	0.306	0.001	0.865	0.000	0.014	0.017	0.099								
		N	496	496	496	496	496	496	496	496	496							
	I have thought about my death	Correlation	.104*	0.024	.114*	-0.018	0.061	0.048	.181**	.132**	-0.004	1.000						
		Sig. (2-taile	0.021	0.591	0.011	0.689	0.174	0.284	0.000	0.003	0.931							
		N	496	496	496	496	496	496	496	496	496	496						
	I have thought about my funeral plans	Correlation	.167**	0.025	0.055	0.044	0.030	0.013	.120**	0.066	-.117**	.477**	1.000					
		Sig. (2-taile	0.000	0.577	0.220	0.324	0.499	0.773	0.007	0.140	0.009	0.000						
		N	496	496	496	496	496	496	496	496	496	496	496					
	I have thought about the death of my loved ones	Correlation	.113*	0.011	0.030	-0.024	0.075	0.065	.121**	.107*	-.118**	.507**	.469**	1.000				
		Sig. (2-taile	0.012	0.806	0.504	0.600	0.093	0.148	0.007	0.017	0.009	0.000	0.000					
		N	496	496	496	496	496	496	496	496	496	496	496	496				
	I avoid discussing death	Correlation	.165**	0.030	.110*	.365**	.139**	-.143**	.112*	.138**	0.023	0.057	0.028	0.066	1.000			
		Sig. (2-taile	0.000	0.508	0.014	0.000	0.002	0.001	0.013	0.002	0.608	0.204	0.527	0.139				
		N	496	496	496	496	496	496	496	496	496	496	496	496	496			
	I think about death more since I became an emergency care provider	Correlation	.273**	-0.015	0.052	.196**	.111*	.100*	.168**	.261**	0.032	.287**	.256**	.307**	.196**	1.000		
		Sig. (2-taile	0.000	0.737	0.246	0.000	0.013	0.027	0.000	0.000	0.482	0.000	0.000	0.000	0.000			
		N	496	496	496	496	496	496	496	496	496	496	496	496	496	496		
	I feel life is too short	Correlation	.136**	0.061	0.086	.112*	0.023	.117**	.154**	.275**	0.063	.268**	.186**	.223**	.144**	.325**	1.000	
		Sig. (2-taile	0.002	0.178	0.057	0.013	0.603	0.009	0.001	0.000	0.159	0.000	0.000	0.000	0.001	0.000		
		N	496	496	496	496	496	496	496	496	496	496	496	496	496	496	496	
	I believe that there is life after death	Correlation	0.004	.129**	-.106*	-0.031	-0.051	.167**	0.033	.216**	-0.034	.148**	.101*	.165**	-0.083	.097*	.305**	1.000
		Sig. (2-taile	0.923	0.004	0.018	0.495	0.260	0.000	0.460	0.000	0.453	0.001	0.025	0.000	0.064	0.030	0.000	
		N	496	496	496	496	496	496	496	496	496	496	496	496	496	496	496	496

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).