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ADAPTATION AND VALIDATION OF AN INSTRUMENT TO MEASURE QUALITY OF END-OF-LIFE CARE IN EMERGENCY DEPARTMENTS

by

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in

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DECLARATION

Student Number: 15228942

I, Beauty Sepelete, declare that the study **Adaptation and validation of an instrument to measure quality of end-of-life care in emergency departments** is my own work and that all sources that have been used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted for any other degree at any other institution.

Name **Date**

ABSTRACT

Introduction: One way of successfully measuring the quality of end-of-life care is by means of practical, applicable and valid questionnaires that focus on quality end-of-life care and can be used to help healthcare professionals to identify what interventions are needed to improve the quality of end-of-life care they deliver.

Background: Dying and end-of-life care is a world-wide concern and healthcare professionals are expected to deliver, evaluate and improve the quality of care delivered. End-of-life care affects the patients' families and healthcare professionals. However the reality is that patients die in the emergency department whether expected or unexpected. Healthcare professionals in the EDs render care to patients of all ages ranging from newborns to elderly patients on a 24-hour basis, including adult patients with end-of-life care needs.

Aim: The aim of the study was to adapt and validate the 'ICU Palliative Care Quality Assessment Tool' used to measure quality end-of-life in an ICU context for the ED.

Research design and methods: A quantitative and descriptive study was conducted with healthcare professionals working in EDs in private and public hospitals in South Africa. The study was conducted in four stages and data was collected over six months by means of an on-line survey to adapt and validate the instrument. The respondents were asked to give feedback on the instructions to respondents, the layout of the instrument, the 10-point Likert scale, and each item.

In terms of the items, the respondents were asked to comment on the relevance, content, and clarity of each of the 61 items. The respondents were given an opportunity to add additional items to the instrument that they considered relevant to the provision of quality end-of-life in the ED (Ranse et al 2014:699). Text boxes were provided for comments or rephrasing of the items. Stage 4 was a pilot study with three hundred and fifteen respondents to validate the instrument.

Results: The results showed a Cronbach's alpha above 80%.

Conclusion: The results therefore validated the 'Quality End-of-life Care Assessment in Emergency Departments' instrument to measure quality end-of-life care in the ED.

Keywords: Adaptation, emergency department, end-of-life care, validation.

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ED	Emergency department
EOLC	End-of-life care

CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Dying and end-of-life care is an international concern and healthcare professionals are expected to deliver, evaluate and improve the quality of care delivered to patients at the end of their lives (Bauchner & Fontanarosa 2016:270). In the 1960s, end-of-life care formed part of palliative care and focused specifically on the oncology patient, but the need for end-of-life care services has expanded to patients with other conditions, such as cardiovascular, cerebral vascular and respiratory disease (Cheung & Chan 2016:9). The concepts *end-of-life care* and *palliative care* are often used interchangeably in literature, but understanding the difference is vital (Cheung & Chan 2016:9).

End-of-life care refers to care delivered by healthcare professionals to patients and their families at the end of the patient's life when death is imminent and normal life-saving treatments are futile (Razmaria 2016:115). The main focus of end-of-life care is offering comfort to patients who are already at the end of their disease process and support to the bereaved family members (Tse, Hung & Pang 2016:224). Traditionally, among the Inuit in Quebec, end-of-life care was practised in people's homes, communities, and hospice facilities, but has now shifted to hospitals due to limited budgets and resources, and challenges to provide end-of-life care to those in need in those traditional environments (Hordyk, Macdonald & Brassard 2016:4). Although most patients at the end of their lives prefer to be nursed and die at home, many of them seek help from healthcare professionals in the emergency department before death occurs and end up dying in the ED (Cheung & Chan 2016:9). The researcher observed that initiating and delivering end-of-life care in the EDs today is fast becoming a reality as EDs are increasingly becoming the default health professionals for patients with end-of-life care needs (Cheung & Chan 2016:9; Bradley, Burney & Hughes 2013:334).

The main focus of healthcare professionals working in the ED is to provide aggressive resuscitative care which is aimed at saving and prolonging the lives of critically ill/injured patients and preventing death (Tse et al 2016:224). However, the reality is that patients die in the ED, whether expected or unexpected. Expected deaths happen when patients with chronic debilitating diseases seek help in the ED and are managed during the terminal phase of their illness, such as a patient diagnosed with cancer. Unexpected deaths can occur when critically ill and injured patients are admitted unexpectedly and deteriorate until they need end-of-life care. The deaths of both these types of patients result in the expanding role of healthcare professionals who need to know how to care for the dying patient in the ED (Tse et al 2016:224; Bradley et al 2013:334). Whether death is expected or unexpected, quality end-of-life care services should be initiated and delivered in the ED (Tse et al 2016:224). Patients in need of end-of-life care, however, require a different approach from the aggressive lifesaving approach usually practised in the ED (George, Phillips, Zaurova, Song, Lamba & Grudzen 2016:108).

The aggressive management approach that has become the norm in the ED makes the context challenging to deliver end-of-life care (Marck, Weil, Lane, Weiland, Philip, Boughey & Jelinek 2014:366; Weiland, Lane, Jelinek, Marck, Weil, Boughey & Phillip 2015:2). In today's busy, chaotic, overcrowded EDs, healthcare professionals work under pressure which leaves little time to practise holistic end-of-life care. The limited time and the fact that many of the healthcare professionals are not trained to provide end-of-life care increase the feeling of discontent and make them feel incompetent to deliver quality end-of-life care in the ED (Ranse, Yates & Coyer 2016:84). Dying with dignity in an environment that is noisy and chaotic, and offers little privacy is not easy to accomplish (Molina, Cortes, Padilla, Caro & Sola 2016:233). The busy ED could deprive the patients in need of end-of-life care the right to die with dignity, leaving the patients, the family as well as the healthcare professionals unhappy and uncomfortable (Molina et al 2016:233). Dying a dignified death and providing support to the dying patients and their families is one of the main objectives for delivering quality end-of-life care in all health care contexts and the ED is no exception (Sola, Cortes, Padilla, Torres, Terron & Molina 2017:20).

Measuring the quality of end-of-life care in healthcare contexts (including the ED) is important as it ensures high standards of care delivery to improve patient outcomes and quality of life (Cornally, Coffey, Daly, McGlade, Weathers et al 2015:243; Luta, Maessen, Egger, Stuck, Goodman & Clough-Gorr 2015:1). Quality end-of-life care enhances patients' and families' physical, emotional and spiritual well-being towards the process of dying, preparing them to die in a dignified way (Gurdogan, Kurt, Aksoy, Kınıcı & Şen 2017:180; Meir, Gallegos, Thomas, Depp, Irwin & Jeste 2016:1). According to Ranse et al (2016:87), quality end-of-life care must include care delivered according to Clarke, Curtis, Luce, Levy et al's (2003:2258) seven domains. The seven domains are patient and family decision making; communication; continuity of care; emotional and practical support; symptom management and comfort care; spiritual support, and emotional and organizational support. These domains or quality indicators can be used to measure end-of-life care quality (see section 2.6; chapter 7 sections 7.1 to 7.7 for discussion of the domains).

Luta, Maessen, Egger, Stuck, Goodman & Clough-Gorr (2015:1) maintain that for end-of-life care to improve, the care currently provided should be accurately measured regardless of the obstacles healthcare professionals may encounter in the ED. One way of successfully measuring the quality of end-of-life care is by means of practical applicable and valid instruments (Conrad, Mücke, Marinova, Burghardt et al 2016:2). According to Cornally et al (2015:246), instruments focusing on quality end-of-life care can be used to help healthcare professionals to identify what interventions are needed to improve the quality of end-of-life care they deliver.

1.2 PROBLEM STATEMENT

Although most patients at the end of their lives prefer to be nursed and die at home, many of them seek help from healthcare professionals in the ED before death occurs and end up dying in the ED (Cheung & Chan 2016:9). The quality of end-of-life care delivered in the ED is currently not measured. Measuring the quality of end-of-life care in all contexts is vital to ensure that a high standard of care is maintained as it may influence the patients' and their families' quality of life and outcome (Cornally et al 2015:245). Quality of care can be measured by using a valid and reliable quality instrument (Ranse et al 2016:84; Luta et al 2015:2).

The researcher conducted a comprehensive literature review but found no instrument that measured quality of end-of-life care in the ED. According to Moon (2017:51), using a pre-validated instrument saves researchers from creating new measures and allows the use of a measure which is known to be reliable and valid. Consequently, the researcher searched for instruments that could be used for measuring quality end-of-life in other contexts. The researcher identified the 'ICU Palliative Care Quality Assessment Tool' developed by Clarke et al (2003:2255) for intensive care units. The instrument was based on Clarke et als' (2003:2255) quality indicators or domains of quality end-of-life care and was developed for and tested in intensive care units. The researcher was unable to find evidence that the instrument has been adapted for or used in other contexts, including the ED. The researcher wished to adapt and validate the instrument for the ED to measure the quality of end-of-life care in the ED by following the adaptation steps suggested by Borsa, Damasio & Bandeira 2012:423-432 Cross-cultural adaptation and validation of psychological instruments. (Moon 2017:51).

1.3 RESEARCH QUESTION

To achieve the purpose, the study wished to answer the following question:

How can an instrument be adapted and validated to measure quality end-of-life care in emergency departments?

1.4 AIM AND OBJECTIVES

The aim of the study was to adapt and validate an instrument to measure the quality of end-of-life care in emergency departments.

In order to achieve the aim, the objectives of the study were to:

- Adapt an instrument used to measure quality end-of-life care in intensive care units for emergency departments.
- Validate the instrument to measure end-of-life care for the emergency departments.

1.5 SIGNIFICANCE AND BENEFITS OF THE STUDY

Measuring the quality of end-of-life care is important to understand and appreciate patients' and family needs (Wright, Lowton, Robert, Grudzen & Grocott 2017:2), improve the end-of-life care delivered (Conrad et al 2016:1; Cornally et al 2016:246), and consequently improve service delivery (Cornally et al 2016:245; Dy, Herr, Bernacki, Kamal, Walling, Ersek & Norton 2016:161) in all contexts, including the ED. No current instrument was available to measure the quality of end-of-life care that included patients, families and healthcare professionals. Using the 'ICU palliative care quality assessment tool' for intensive care units enabled the researcher to adapt and validate it to assess the quality of care delivered to dying patients in the ED.

1.6 DELINEATION

Delineation refers to the boundaries limiting the generalisation of the results of a study (Burns & Grove 2012:40). Nurses and doctors working in the ED with two years' experience were included as participants. 'ICU palliative care quality assessment tool', which was guided by Clarke et al's (2003:2255) seven domains, was selected and adapted for use in the ED. The focus of the study was to adapt and validate the instrument and not to measure the quality of end-of-life care in EDs.

1.7 CONCEPTUAL FRAMEWORK

Clarke et al's (2003:2255) seven quality indicators or domains guided the study (Ranse et al 2016:88). The seven domains are: 1) patient and family-centred decision making, 2) communication, 3) continuity of care, 4) emotional and practical support, 5) symptom management and comfort care, 6) spiritual support, and 7) emotional and organisational support for clinicians.

1.7.1 Communication within the team and with patients and families

Clarke et al (2003:2256) state that it is vital to prepare patients and families for the dying process. Witkamp, Droger, Janssens, Zuylen and Heide (2016:236) found that when patients and families were involved in advance in explanation and counselling about the pending death of their loved one, they prepared themselves and awaited the death process harmoniously. Communication focuses on regular meetings with patients, families and interdisciplinary team members to discuss the patient's condition, plan of care, and treatment while exploring the patient's and family's understanding of the patient's condition, and cultural and spiritual issues that could influence their coping strategies. Witkamp et al (2016:236) emphasise that during communication with patients and their families regarding end-of-life, the discussion and explanations should be in layman's terms, which make the family feel that their roles and presence are acknowledged.

1.7.2 Patient- and family-centred decision making

Patients and families value patient-centred behaviour from healthcare professionals when delivering care and sharing information which is directed to meet their needs (McConnell, McCance & Melby 2016:41). Shared decision making among healthcare professionals, patients and their families must be the basis of all discussions and resolutions involved in end-of-life care (McEwan & Silverberg 2016:667). In this domain, the patient and family/significant other are seen as one, which implies that the patient's and the family's preferences should be respected throughout decision-making about end-of-life care (Clarke et al 2003:2258). The appropriate treatment and goal of treatment must be clear and discussed with patients and their families (Clarke et al 2003:2258).

1.7.3 Continuity of care

Continuity of care is about maximising and ensuring the continuity of end-of-life care across interdisciplinary team members, disciplines and contexts. New doctors involved in the care of patients should be oriented regarding the patient and the family's status and care, and the patient and family should be introduced and prepared for any change in the team management of their case (Clarke et al 2003:2258). Easy access to care, management, continuity and good care should be provided to patients any time they need care to help them feel safer (McCaffrey, Bradley, Ratcliffe & Currow 2016:323).

1.7.4 Emotional and practical support for patients and families

Providing end-of-life care to patients and their families is a complicated task. Kisorio and Langley (2015:31) found continuous support for dying patients and their families vital to ensure quality end-of-life care. The family must be oriented to the care context, visiting time, and other relevant resources and support systems. Healthcare professionals should provide privacy, respect and support the patient's and family's culture, beliefs and traditions (Clarke et al 2003:2258). Offering patients support through ensuring that their families are present all the time and participating in their daily care prevents feelings of isolation which is very important during end-of-life care (Kisorio & Langley 2015:36). Supporting the patient and the family throughout the management journey is vital. Families specifically require further bereavement support after the patient's death.

1.7.5 Symptom management and comfort care

Providing end-of-life care, giving support and comfort in the healthcare context remains vital (Mayland, Mulholland, Gambles, Ellershaw & Stewart 2017:1). Best clinical practices and evidence-based care should be identified and followed when caring for the patient's comfort and addressing symptoms of dying (McEwan & Silverberg 2016:667). Symptom management could be done with pharmacological or non-pharmacological measures aimed at making the patient and the family comfortable (Clarke et al 2003:2257). Activities of daily living and basic needs should be provided to patients and clinicians should be available and present to avoid the patient dying alone (Clarke et al 2003:2258). Care should focus on facilitating and assisting comfort while improving physical distress and pain (Sola, Cortes, Padilla, Torres, Terron & Molina 2017:21).

1.7.6 Spiritual support

Spiritual support is important for patients to ensure that they die with dignity. In Turkey, Gurdogan, Kurt, Aksoy, Kinici and Sen (2017:181) found that spiritual support had a positive effect on patients' and families' perception of the disease process during end-of-life. Identifying patient and family needs before implementing interventions to provide spiritual support ensured quality end-of-life care (Gurdogan, et al 2017:181). Religious representatives should be allowed to support the patient and the family if that is their wish (Clarke et al 2003:2258).

1.7.7 Emotional and organisational support for doctors and nurses

Healthcare professionals (doctors and nurses) delivering end-of-life care in the ED need to be emotionally and spiritually supported to be able to deliver quality end-of-life care to patients and families (Ranse et al 2016:87). Support from the organisation in the form of training on end-of-life care can improve the quality of end-of-life care delivered (Ranse et al 2016:88; Clarke et al 2003:2258). Healthcare professionals attending to dying patients can also be supported through adjustment of staff rotation schedules to provide continuity of care to the patients and their families to ensure quality end-of-life care. Support groups for healthcare professionals and counselling sessions should be readily available (Clarke et al. 2003:2258).

1.8 STUDY SETTING

The setting refers to the site where data is collected for a study (Polit & Beck, 2017:47). In this study, the setting or context included EDs in private and public hospitals South Africa. Healthcare professionals in the EDs render care to patients of all ages ranging from newborns to elderly patients on a 24-hour basis, including adult patients with end-of-life care needs.

1.9 DEFINITION OF KEY TERMS

For the purposes of this study, the following key terms were used as defined below.

1.9.1 Adaptation

Adaptation refers to the translation, relevance and applicability of an instrument to a specific population and/or context as well as using the language (wording) that is understood and used in the context (Moon 2017:51; Borsa, Damasio & Bandeira 2012:423). In this study, *adaptatio*n referred to the relevance and wording of items of Clarke et al. (2003) ICU palliative care quality assessment tool to measure the quality end-of-life care delivered in the ED context.

1.9.2 Emergency department

An emergency department is a unit in a hospital, which renders a 24-hour service to a non-scheduled patient population with anticipated emergency needs. Healthcare professionals in emergency departments deliver care to patients with resuscitative needs due to life-threatening situations that need immediate intervention (McEwan & Silverberg 2016:667). Healthcare professionals in the ED also deliver care to patients of all ages presenting with minor to major emergencies. In this study, the ED was a unit in a public or private hospital in South Africa where healthcare professionals delivered 24-hour care to patients with end-of-life care needs.

1.9.3 End-of-life care

End-of-life care refers to the care that healthcare professionals deliver to patients and their families at the end of the patient’s life when death is imminent and normal life-saving treatment is futile (Razmaria 2016:115). In this study, this applied to adult patients receiving end-of-life care by healthcare professionals in the ED.

1.9.4 Expert

Recommendations for the selection of experts for content validity assessment include the need for expert knowledge on the subject, clinical experience, published or presented in the area or have expertise in instrument development (Grant & Davis 1997). In this study, an expert referred to a medical doctor or registered nurse working in an ED for two or more years and who had a self-reported interest or experience in delivering end-of-life care in the ED and/or have an interest in end-of-life care in the ED and/or have expertise in instrument development.

1.9.5 Healthcare professionals

In this study, healthcare professionals referred to all medical doctors registered with the Health Professionals Council of South Africa (HPCSA) as well as all registered nurses registered with the South African Nursing Council (SANC) and working in an ED in Tshwane and Johannesburg (National Health Act 61:10 section 58(1)(q) of the Nursing Act,2005(Act 33 of 2005) No 36935

1.9.6 Quality end-of-life care

Quality end-of-life care focuses on the effective management of a patient's physical, emotional, spiritual and ethical needs while taking into consideration the patient's and the families' preferences for end-of-life care (Meier 2010:1). In this study, quality end-of-life care referred to end-of-life care delivered to patients by healthcare professionals in the ED based on Clarke et al's (2003:2255) domains.

1.9.7 Validation

In this study, validation referred to testing whether the adapted instrument to measure quality end-of-life care in the ED was valid in terms of construct and content validity (Peirce et al 2016:1657).

1.10 ETHICAL CONSIDERATIONS

According to Polit and Beck, (2017:727) ethics refers to a structure of moral values concerned by degree to that research procedure, legal and social procedures requirement are observed and practiced, to the study participants. Research ethics provide moral guidelines and to give the researcher more responsibility towards the research participants. For studies involving humans' attention must be given to ethical consideration. Before commencement of data collection for the study the approval was obtained from the ethics committee of the University of Pretoria, Faculty of Health Sciences (162/2018). See Annexure A.2. Participation was voluntary and participation on the survey implied consent. The experts sent their feedback anonymously and no personal details were collected to ensure confidentiality.

The ethical conduct was based on the three principles named: beneficence, respect for human dignity and justice as described by Polit and Beck (2017:139) from the Belmont report. With regard to the principle of beneficence the researcher avoided harm to the participants by securing the wellbeing and made the benefits of the research clear to the participants (Polit and Beck, 2017:139). Information collected from the participants was kept confidential. Participants were informed that they may withdraw from the study anytime they feel like.

Respect for human dignity involves the right to self-rule or the determination and the right to full disclosure, meaning that the participants voluntarily participates or not participates in the research (Polit and Beck,2017:140). The researcher provided the participants with complete information for them to make informed decision to participate willingly in the study. Informed consent was obtained from the participants in every stage and participants informed that they may withdraw from the study at any point. The researcher informed the respondents of the aims, objectives, significance and benefits as well as data-collection methods of the study (Polit& Beck 2017:139). The respondents were informed that participation in the study was voluntary and in their own personal capacity. They were informed that they were free to withdraw from the study at any time. The respondents' confidentiality and anonymity was maintained throughout the study (Polit& Beck 2017:141).

Justice refers to the participant's right to be treated fairly from the selection to the end of the study and for them to have their privacy respected (Polit and Beck, 2017:141). No names were mentioned in any stages of the research and confidentiality of the participants and the information was maintained.

1.11 SUMMARY

This chapter described the background to, problem, purpose, objectives and significance, and conceptual foundation of the study, and defined key words used in the study.

Chapter 2 discusses the literature review undertaken for the study.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 described the aims, objectives, research design and methodology of the study. This chapter discusses the literature review conducted for the study. The literature review covered a brief history of end-of-life care (EoLC), models of EoLC, the value of EoLC, and the importance of measuring the quality of EoLC.

2.2 RATIONALE FOR LITERATURE REVIEW

A literature review is a summary of what has been published on a specific subject for the purpose of conveying what is currently known about the topic (Polit & Beck 2017:733). A literature review is the exploration, critical assessment and production of current information appropriate to the research problem (Hart 2016:5).

The purpose of the literature review was to examine the existing theoretical knowledge on the topic of end-of-life care (EoLC) in the ED and differentiate what has been done from what needs to be done (Hart 2016:31). In addition, it wished to justify the practical importance of the problem of measuring quality of EoLC in the ED and share ideas and theory to support potential solutions (Hart 2016:31).

2.3 HISTORICAL OVERVIEW

Until the nineteenth and early twentieth century, taking care of dying patients and their families was the job of the family and the church. In the mid-twentieth century, Dr Cicely Saunders, a British nurse and with a doctoral degree, recognised the inadequacy of the care of the dying that was offered in hospitals. Saunders conceptualised modern end-of-life care and founded the first modern hospice, St Christopher's, in London in 1967. Saunders was responsible for establishing the discipline and the culture of palliative care, introduced effective pain management, and insisted that dying people needed dignity, compassion and respect (Hammer, Melberg & Fowler 2013:200; Lutz 2011:304). Saunders stressed the importance of combining excellent medical and nursing care with holistic support that recognised practical, emotional, social, and spiritual need. Moreover, she saw the dying person and the family and significant others as the unit of care and developed bereavement services at St Christopher's Hospice to extend support beyond the death of the patient. In 1969 she pioneered the first home care team thereby taking hospice and palliative care and philosophy out into the community (Hammer et al 2013:201). Although many patients and their significant others would prefer to be nursed at home at the end of their life, unmanageable symptoms, financial issues and limited access to palliative care services force them to seek help from the ED (Cheung & Chan 2016:9).

In Australia, Marck, Weil, Lane, Weiland, Philip, Boughey and Jelinek (2014:366) found that patients with cancer were increasingly presenting to EDs for end-of-life care. The shift in the focus needed to deliver end-of-life care in the ED is not only challenging, but causes conflicting roles for the healthcare professionals, leaving them feeling discontented due to failure in delivering holistic care to those patients (Marck et al.2014:366).

2.4 END-OF-LIFE CARE

Death is inevitable, and people die every day from different causes and in different settings. Some die alone, whilst others want to be surrounded by family members and in the comfort of their own home, with enough time to say their goodbyes (Bauchner & Fontanarosa 2016:270). To face death is a deep and painful encounter for patients, significant others, family members, caregivers and healthcare professionals (Wolf, Berlinger & Jennings 2015:678). In the ED, too, death has never been an easy situation - whether the patient has been chronically ill or a previously well patient (Pal, Kuan, Koh, Venugopal & Ibrahim 2017:129).

The World Health Organization (WHO 2015) 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, psychological and spiritual". End-of-life care refers to the dying process and the term is used interchangeably with palliative, comfort and terminal care (Abu-Ghori et al 2016:22). For the purpose of the study and in the literature review, the term *end-of-life* was used. Razmaria (2016:115) defines end-of-life care as "the care that healthcare professionals deliver to patients and their families at the end of the patient's life when death is imminent and normal life-saving treatments are futile". End-of-life care is a collaborative approach and includes a network of significant others such as family members, friends, church members, hospice caregivers and healthcare professionals (Razmaria 2016:115). End-of-life care is patient-centred and family-focused on improving quality of life and supporting the family to better understand their patient's illness (Guo & Jacelon 2014:933).

The purpose of end-of-life care is to relieve the suffering of patients through intensive physical, psychosocial and spiritual care which is focused on promoting the dignity of the individual person (Guo & Jacelon 2014:932).The aim therefore is to make dying a pain-free process that holistically cares for, supports, and provides comfort relief of symptoms in order to give patients quality end of life, and addresses the communication and decision-making needs of the patients receiving end-of-life care and their families (Kelley & Morrison 2015:747).

End-of-life care is important irrespective of whether the condition is acute or chronic and whether it is in an early or late stage it may be extended beyond the patient's death to the bereaved family members (Cook & Rocker 2014:2506). The timing and setting of palliative care have been found to have a constructive effect on several clinical outcomes like symptom distress, quality of life, contentment and survival (Hui, Kim, Roquemore et al 2014:1743). End-of-life care improves contact with psychosocial facilities and introduces necessary resources to home settings hence decreasing the need for serious urgent care (Hui et al 2014:1748).

End-of-life care is offered in two forms: primary and specialist end-of-life care. Primary end-of-life care involves the basic skills all healthcare professionals should possess, namely management of pain and symptoms, basic management of depression and anxiety, simple family discussions on the prognosis, the goals of treatment and the suffering (Joynt & Jha 2013:1174). Specialist end-of-life care involves advanced skills for managing more complex and difficult cases such as assisting with conflict resolution regarding goals and methods of treatment of the dying patient, with the patient and among families and staff (Joynt & Jha 2013:1174).

End-of-life care is carried out through different approaches and in diverse settings and has become synonymous with physical, psychological, social, and spiritual support of patients and currently rendered by multidisciplinary team (Yates 2017:179). Many patients receive end-of-life care from different sources including home-based care nurses, primary care practitioners, nursing homes and hospitals (Bainbridge & Seow 2018:456). End-of-life care provided by hospice aims at improving quality of care for patients and their families (Guo & Jacelon 2014:933). Home hospice refers to end-of-life care provided at home and provided by physicians and other professionals, such as social workers, priests and bereavement counsellors (Bainbridge, Giruparajah, Zou & Seow

2018:436). Most patients prefer end-of-life care to be provided at home as they prefer to die in the comfort of their own homes (Bainbridge et al 2018:437).

2.5 MODELS OF END-OF-LIFE CARE

The aim of the study was to adapt and validate an instrument to measure the quality of end-of-life care in emergency departments (EDs). The researcher conducted a comprehensive literature review but found no instrument that measured quality of end-of-life care in the ED. Consequently, the researcher searched for instruments that could be used for measuring quality end-of-life in other contexts. The researcher reviewed models of end-of-life care in an effort to find a model that was supported by an instrument that could assess and guide EoLC in the ED. Three models developed for palliative care in the ED were considered, namely:

- General plus specialist palliative care (Quill & Abernethy 2013:1173-1175)
- The TELOS best-practice model (Burns, Jacobs & Jacobs 2011:97-101)
- A risk model for emergency department palliative care needs assessment using the Screen for Palliative End-of-Life care needs in the Emergency Department (SPEED)(TH347-A) (Moulia, Binney, Vanairsdale, Janssens & Quest 2015:351).

The models of care describe the best practices for end-of-life care in hospital settings, EDs and ICU. In addition these models can be used to assist and/or improve end-of-life care.

2.5.1 General plus specialist palliative care

Palliative care has been practised informally for centuries. The demand for palliative care specialists has increased rapidly, however, since timely palliative care consultations have been shown to improve quality of care, reduce overall costs and sometimes increase longevity (Quill & Abernethy 2013:1173). Quill and Abernethy (2013:1173) point out that the role of palliative care has expanded so that palliative treatment is now also provided in the earlier stages of disease, improving both quality of care and medical decision making regardless of the stage of the illness. They maintain that some core elements of palliative care, such as basic symptom management, should be part of care delivered by any practitioner while other more complex skills should be the specialist's domain. Many people are living longer with an increased illness burden, which will also challenge the palliative care workforce. According to Quill and Abernethy (2013:1174), the estimated increased demand for palliative care thus requires a care model that distinguishes primary palliative care from specialist palliative care so that they can coexist and support each other.

2.5.2 The trauma end-of-life optimum support (TELOS) best-practice model

Trauma has been the leading cause of death of individuals between 15 and 44 years of age in the United States of America for many years. The development of the trauma end-of-life optimum support (TELOS) best-practice model was a result of a national call to improve end-of-life care for trauma patients and their families (Burns, Jacobs & Jacobs 2011:97). The model highlights the need to provide victims and their significant others optimal end-of-life care. The model describes best practices for end-of-life care in pre-hospital settings, the ED, and the ICU and focuses on six clinical domains, namely decision-making, communication, psychological care, physical care, spiritual care, and culturally sensitive care (Burns et al 2011:97). The model also identified several obstacles to providing quality end-of-life care in the ED, including being too busy; dealing with angry family members; lack of appropriate areas for privacy, and the patient's family not understanding what life-saving measures involved (Burns et al 2011:98-99).

2.5.3 Screen for Palliative End-of-Life care needs in the Emergency Department (SPEED)(TH347-A)

The researcher also considered Moulia, Binney, Vanairsdale, Janssens and Quest's (2015:351) risk model for ED palliative care needs assessment using the Screen for Palliative and End-of-Life care needs in the ED (SPEED). The aim of the multivariate logistic regression model developed was to predict palliative care events (PCEs) for cancer patients. The model looked at significant decisions regarding patients' treatment needs, determined the next care area, and classified patients who would benefit from early palliative care consultation based on the SPEED score (Moulia et al 2015:351). Moulia et al (2015:351) pointed out that the model needed a larger dataset for additional validation.

2.6 CLARKE ET AL'S (2003) SEVEN DOMAINS OF QUALITY END-OF-LIFE CARE

The researcher identified the 'ICU Palliative Care Quality Assessment Tool' developed by Clarke, Randall Curtis, Luce and Levy (2003:2258) for intensive care units (ICUs). Clarke et al (2003:2256) identified the need for improving EoLC in ICUs and developed seven quality indicators or domains for EoLC in ICUs. Healthcare professionals should carry out the items in each domain to improve quality EoLC in an ICU (Ranse et al 2014:699). After studying end-of-life care in the intensive care environment, Clarke et al (2003:2255) identified and developed the first five quality indicators or domains for end-of-life care, using the Delphi approach. After two further reviews the final domains were included (Clarke et al 2003:2256). The seven domains are patient and family decision making; communication; continuity of care; emotional and practical support; symptom management and comfort care; spiritual support, and emotional and organizational support.

The researcher used Clarke et al's model in this study as it focuses on the quality of EoLC rendered to patients and their families. It also takes into consideration how healthcare professionals deliver quality EoLC. The seven domains of end-of-life care have been found theoretically meaningful and cover most aspects of quality EoLC. Moreover, the model equips healthcare professionals to assess the care delivered and then plan and implement strategies to improve the quality of EoLC delivered in the ICU (Ranse et al 2016:88).

These domains or quality indicators can be used to measure end-of-life care quality and assist healthcare professionals to deliver persistent quality end-of-life care (Ranse et al 2016:87).

2.6.1 Communication within the team and with patients and families

Communication between healthcare professionals and with patients and families is important for patients on EoLC and their relatives (Clarke et al 2003:2257). Healthcare professionals should have effective communication skills about end-of-life care, particularly knowing what to say and when to say it as they deal with strong and painful emotions (Gillett, O'Neill & Bloomfield 2015:395).

Early, well-timed discussion of care preferences and prognosis may give patients and families time to arrange for end-of-life care and determine that care is in line with their values and wishes and improves satisfaction with care offered thereby also improving quality of life (Walczak, Butow, Tattersall, Davidson et al 2017:32). Information provided to both patients and their families should be personalised according to their needs and they should be encouraged to ask questions and further the discussion (Yates 2017:187). In end-of-life care, the goal of communication and decision making is to achieve common understanding about patients' morals and preferences that will assist in care plans that are consistent with preferences and morals (Sinuff, Dodek, You, Barwich, Taylor et al 2015:1071).

Information to patients and family's needs to be communicated in a simple, polite way and with compassion to establish good relationships among the patients families and healthcare professionals while at the same time preparing the patients and family for a dignified dying process (Busolo & Woodgate 2016:297; Noome, Dijkstra, van Leeuwen & Vloet 2016:62). One member of the family should be identified to act as a spokesperson for the entire family, and the patient and family to be informed of all the information good or bad in a delicate, clear manner and in appropriate surroundings (Clarke et al 2003:2258).

Adequate discussion and explanation of results to patients and families provides enough information to make well-informed decisions (Busolo & Woodgate 2016:297). Better decision making has the potential to increase patient-centred care and decrease unnecessary hurt to patients and families (Sinuff et al 2015:1071). Patients' families should be met regularly to inform them of patient status and address distressing issues (Clarke et al 2003:2258). Good communication with relevant information allays anxiety, clears confusion, and reduces fear of the unknown, and helps both patients and families to acquire the right skills to cope with and understand the type of care expected (Busolo & Woodgate 2016:297). Clear, thoughtful and well-timed communication and discussion is vital to ensure that good quality care is rendered to patients on end-of-life care and their families (Mayland, Mulholland, Gambles, Ellershaw & Stewart 2017:9). Relevant communication and appropriate actions by the healthcare team have an important and helpful impact on the heartbroken family members (Pal et al 2017:132). Clear, honest communication contributes to family satisfaction with EoLC and family happiness about meetings improves when physicians talk less and listen attentively (Cook & Rocker 2014:2508).

Family need counselling and discussion about the patients' condition, end-of-life expectations, and comfort measures to satisfy them (Nadin, Miandad, Kelley et al 2017:5). A collaborative discussion among clinicians is important to enable decisions about end-of-life care (Brooks, Manias & Nicholson 2017:161). Clear open communication between patients and healthcare professionals would enhance end-of-life care practices (Brooks et al 2017:161). Encouraging communication and a teamwork culture is crucial to achieve safe and high quality care during end-of-life care and this teamwork discussion helps patients and families transition from vigorous treatment to starting end-of-life care (Brooks et al 2017:161).

2.6.2 Patient- and family-centred decision making

It is important to honour the values and treatment preferences of patients on end-of-life care as it provides quality patient-centred management (Hammer et al 2016:202). During end-of-life care decision-making is vital. Decision-making starts with communication between patient, family and healthcare professionals, by sharing information to support the decision and thus create an opportunity for patient/family involvement and participation (McCormack et al, 2011:1091). The level of patient and family involvement in decision- making depends on patients' preferences and how critically ill they are (McCormack et al, 2011:1091).

Sy, Tan and Krishna (2015:169) stress that patients decisions and choices should be respected, with no interference from outside influences. In addition, confidentiality and truthfulness should be maintained for the patient and family to make appropriate decisions based on the medical details (Sy et al 2015:169). Early shared decision making in regard to preferences and values is vital for patients and families and at times may need surrogate decision makers, which may be a problem for families (Yamamoto, Arao, Masutani, Aoki et al 2017:862). Despite patients being crucial to decision making, their families contribute considerably to decisions as they make decisions with patients or on behalf of the patients (Yamamoto et al 2017:863).

Family members should be assisted in evaluating the benefits and burdens of other treatment choices as the patient's condition changes (Clarke et al 2003:2258). Healthcare professionals have to provide information about diverse options of treatment, management, and then make recommendations working with the patients and their families (Hammer et al 2016:203). Any decision making by the healthcare professional team should include patients' and families' preferences (Clarke et al 2003:2258). Conflicts for decision making among the family should be assessed and legal guidelines and ethical issues followed for patients and families who do not have the capacity to do so (Clarke et al 2003:2258). The physician should share the information but undertake the main accountability for decision making, and when the patient makes the decision the physician has an advisory role (Cook & Rocker 2014:2508).

Patient-centred decision making involves not only talking about treatment, but asking the patient first about the extent of their preferred involvement (Hammer et al 2016:203).Valid analytical facts are an important factor of end-of-life care considerations (Cook & Rocker 2014:2508). Physicians' requesting families' wishes for recommendations can be an opening point for shared discussion about plans (Cook & Rocker 2014:2509).

Decision-making starts with communication between patient and healthcare professional, by sharing information to support the decision and thus create an opportunity for patient involvement and participation (McCormack et al, 2011:1091). The level of patient involvement in decision- making depends on patients' preferences and how critically ill they are (McCormack et al, 2011:1091). Patient-centred communication is used to change the dynamics of decision-making to shared decision- making where patients are equal partners and actively involved in the decisions (Saha & Beach, 2011:387). Shared decision-making does not give patients more responsibility, but their concerns and preferences are used to direct the care decisions. Patients' perception of shared decision-making is that healthcare professionals understand their emotional and cognitive needs, preferences and concerns which the healthcare professionals use to then suggest a path (Saha & Beach, 2011:387). Patients are more likely to follow healthcare professionals' suggested path when having a choice and a voice (Saha & Beach, 2011:389). As patient-centred communication has evolved in healthcare, it has become a core element in quality care programmes and patients prefer shared decision-making.

2.6.3 Continuity of care

Continuity of care refers to the degree to which a number of healthcare services are practised, linked and logical with patient's health care needs (Den Herder-van der Eeden, Hasselaar, Payne, Varey et al 2017:946). Interdisciplinary team members bring diverse expertise in assessing, managing and delivering relevant care and provide continuing information throughout the care and easy referrals to other healthcare professionals (Busolo & Woodgate 2016:298). Continuity of care involves having continuous therapeutic relationships with one or more healthcare providers to achieve the quality and support the dying process (Den Herder-van der Eeden et al 2017:949). Patients and families should be informed about modification of clinicians and new clinicians introduced to patients and family members and oriented on the patients' condition (Clarke et al 2003:2258).

Patients on end-of-life care and their families will experience continuity of care if they have available reliable healthcare professionals rendering multidisciplinary care with regular sharing of information with all other healthcare professionals involved in the care of the patients (Den Herder-van der Eeden et al 2017:1). Maximised continuity of care gives patients and families an optimistic feeling about care (Den Herder-van-Eeden et al 2017:3). Rendering of care to patients on end-of-life care must be continuous in accordance with patients' needs, not based on prognosis (Abu-Ghori et al 2016:26).

Continuity of care should be of the highest level among the healthcare professionals and consultants (Clarke et al 2003:2258). Teamwork has always been considered necessary to holistically meet the different needs of patients on end-of-life care, when each team member knows the patient, family and renders continuous caring mutual relationship (Klarare, Rasmussen, Fossum, Fürst, Hansson & Hagelin 2017:181). Healthcare professionals should provide and manage care with a broad picture of the situation thus the care they provide should include more than managing the patient's symptoms (Klarare et al 2017:186).

2.6.4 Emotional and practical support for patients and families

Emotional and practical support refers to the support people get when faced with stressful and painful situations. This support gives a sense of belonging and being understood and supported by significant others when faced with emotional distress (Busolo & Woodgate 2016:296). It is important to give support to patients on end-of-life care to safeguard their comfort during the dying process (Kisorio & Langley 2016:36).

The emotional needs of patients on end-of-life care and their families need to be explored and attended to and their privacy maintained (Clarke et al 2003:2258). Families of patients on end-of-life care feel that the presence of the healthcare professionals gives them more comfort that strengthens them during the dying process and after their patients have died (Kisorio & Langley 2016:36).

The emotional distress that is regularly experienced by patients on end-of-life care and their families is often due to their unmet emotional, physical, spiritual and practical needs (Busolo & Woodgate 2016:296). Patients and family relationships and their communication style should be supported and strengthened (Clarke et al 2003:2258). Family members, relatives and significant others need emotional care and support equally as much as the patients on EoLC (Noome et al 2015:57). Significant others and family members experience burden and have their own personal, social, financial and emotional needs at the same time as caring for patients on end-of-life care hence measuring the family's needs and patients' needs may assist clinicians to plan more holistic care (Bausewein, Daveson, Currow, Downing, Deliens et al 2016:10). Patients' and families' cultural beliefs and values should be respected and supported at all times (Clarke et al 2003:2258). Families should be given proper orientation to the ward setup, visiting times, available and nearby resources, and the bereavement programmes (Clarke et al 2003:2258).

2.6.5 Symptom management and comfort care

From the clinical background, multiple symptoms must be included in the measure for the assessment of full experience and symptom burden of the patients as some patients may not mention all their symptoms unless asked (Bausewein et al 2016:10). Rendering considerate and comfort care is important during end-of-life care and actual pain and symptom management gives patients quality end-of-life care (Abu-Ghori et al 2016:26). Pain is the most common concern with patients on end-of-life care and must be managed properly (Nadin et al 2017:5). Patients should be assisted with activities of daily living which include bathing, feeding and assuming the most comfortable position to ease the pain (Clarke et al 2003:2258).

Symptom management must be based on the need of the patients, not on the disease prognosis (Nadin et al 2017:2). With the nature of symptoms, both pharmacological and non-pharmacological methods of symptom management are required to assist the patients (Yates 2017:185). After interventions symptoms must be reassessed and documented, and pharmacological and non-pharmacological procedures should be ensured to give highest level of comfort preferred by the patients and their families' (Clarke et al 2003:2258). Unnecessary tests and invasive procedures should be avoided and best clinical practices for life-sustaining treatment and withdrawal must be carried out in a way that does not cause more suffering to patients and their families (Clarke et al 2003:2258).

2.6.6 Spiritual support

Spirituality is often disregarded during patients' assessment and routine discussions consequently using an outcome measure which includes one or more items that relates to spirituality may assist in identifying areas that may require further support and investigation (Bausewein et al 2016:10). Spiritual support relates to individuals' need to find the meaning of life and the need to be connected to their religious affiliation, and patients on end-of-life care benefit from religious interventions and support (Busolo & Woodgate 2016:297). Spirituality implies and embraces preserving patients' hope, assisting them to find the importance of life and assisting them to have a fighting spirit as positivity of overcoming the illness is important for patients on end-of-life care (Guo & Jacelon 2014:935).

Spirituality expresses many aspects of individuals' personality and their perceptions of the purpose of life and is regarded as a basis to turn to and rely on when faced with challenging situations in life (Gualdani & Pegoli 2014:175). For many people, end-of-life care activates a lot of questions about death, life and suffering, so physicians should ask questions concerning spiritual beliefs that may endure on experiences with respect to illness (Cook & Rocker 2014:2509). Patients' beliefs may shape their lives and are important during end-of-life care (Cook & Rocker 2014:2509).

Spiritual care is important not only to the patient but to the family as well as they have to deal with the impending death of their loved one, deal with demanding conditions, difficult decision making in regard to the patient (Gualdani & Pegoli 2014:175). Clinicians have to realise how spirituality can influence surviving both positively or undesirably (Cook and Rocker 2014:2509). Spiritual care is regarded as an essential component of care for patients on end-of-life care as this time tends to challenge individual beliefs and values (Gurdongan et al 2017:180). Patients' and their family's spiritual needs should be evaluated on a daily basis and recognised, and accessibility to their own spiritual ways should be encouraged and supported (Clarke et al 2003:2258). Spiritual support is important for holistic care and for patients to die with dignity (Gualdani & Pegoli 2014:176). Spirituality has to be taken as part of patients' vital signs that require to be routinely observed and included in their daily care plan as it impacts on their health outcomes (Gomez-Castillo, Hirsch, Groninger, Baker et al 2015:728).

Progressive diseases affect personal life hence cultural and social needs must be evaluated as these domains influence patients' experience of symptoms (Bausewein et al 2016:10). The spiritual and cultural requirements of dying patients and their families have to be taken as important components of providing quality end-of-life care in hospitals (Abu-Ghori et al 2016:22). Family members of patients on end-of-life care may provide spiritual care to their dying loved ones (Kongsuwan, Matchim, Nilmanat, Locsin, Tanioka & Yasuhara 2016:136)

Healthcare professionals' involvement of patients in discussions about spirituality brings about better patient care and assists patients to cope with their illness (Becker, Wright & Schmit 2017:149). Offering patients and their families a prayer and reading Scripture to them are the most common form of spiritual support (LeBaron, Smith, Quiñones, Nibecker et al 2016:674). Being satisfied with their spirituality can nurture end-of-life care patients' feelings of achievement and fulfilment during dying and assist them to die peacefully (Guo

& Jacelon 2014:935). Spirituality improves end-of-life care and enhances quality of life (Gualdini & Pegoli 2014:176).

2.6.7 Emotional and organisational support for doctors and nurses

The natural debriefing of healthcare professionals after a patient dies assists in enabling closure as there is a of lot stress in the workplace. Healthcare professionals caring for patients on end-of-life care must be supported emotionally and physically and their staffing patterns should be adjusted to maximise quality care provided to patients (Clarke et al 2003:2258). Informal briefing, resident meetings together with other professionals, improved work tasks and new approaches may assist clinicians to manage grief (Cook & Rocker 2014:2510). Proper bereavement counselling intended for involved healthcare professionals may improve coping and inspire personnel to adopt expert coping strategies (Cook & Rocker 2014:2510).

It is important to educate healthcare professionals about end-of-life care (Nadin et al 2017:5). Organisational support is necessary to assist healthcare professionals to cope with moral distress, improve skills, and identify and manage ethical discordance based on clinical decision making (Wolf, Perhats, Delao, Moon, Clark & Zavotsky 2016:37-46). In Australia, Brooks, Manias & Nicholson (2017:165) identified the need for an organised education programme to equip all healthcare professionals working with patients on end-of-life care with relevant knowledge and skills.

Support and counselling groups should be established for healthcare professionals taking care of patients on end-of-life care (Clarke et al 2003:2258). Staffing patterns should be adjusted to meet the high demands of patients on end-of-life care (Abu-Ghori et al 2016:27). Regular communication among the interdisciplinary team in relation to goals of care should be established (Clarke et al 2003:2258). Palliative care specialists, pastors and some consultants should teach healthcare professionals taking care of patients on end-of-life care and some rituals should be dedicated to and conducted for staff members to mark the death of patients (Clarke et al 2003:2258).

To render optimal end-of-life care, healthcare professionals must be efficiently prepared and given support by healthcare organisations (Brooks et al 2017:161). Organisations should have procedures which encourage medical teams to provide guidance in discussing and establishing early end-of-life care plans when needed (Brooks et al 2017:165). It is important to support staff members with debriefing gatherings and give them time to be together and discuss moments with each other and relate their experiences (Gualdani & Pegoli 2014:176).

To improve the quality of care usually involves changes in the organization and values of the hospital and the full support of the hospital administration (Wolf, Berlinger & Jennings 2015:679). Training should be provided for all healthcare professionals caring for patients on end-of-life care to help support informed decision making under stressful conditions (Wolf et al 2015:681). The organisation should develop and introduce organised procedures to assist healthcare professionals' and decision makers' create goals, document preferences and produce care plans (Wolf et al 2015:681).

2.7 END-OF-LIFE CARE

Death is unavoidable, and people die every day from different causes and in different environments; some die alone and others want to be surrounded by family members in the comfort of their own homes and have enough time to say their goodbyes (Bauchner & Fontanarosa 2016:270). Death has never been an easy situation especially in the ED whether the patient has been chronically ill or in a previously well patient (Pal, Kuan, Koh et al 2017:132; Nadin et al 2017:1).

2.7.1 Patients to receive end-of-life care

Many patients seek help or die in the ED as a result of old age, or chronic debilitating diseases and traumatic events. Some patients are terminally ill and have comorbidity and are impaired cognitively (Wang & Chan 2015:1711). Other patients prefer to die in hospital as they perceive dying at home as frightening and lonely (Mayland et al 2017:316).

2.7.2 Aim of end-of-life care

The main focus of end-of-life care is to offer comfort to patients, who are already at the end of their disease process, and support the bereaved families (Tse, Hung & Pang 2016:224). The end-of-life care objectives are to provide dignity and quality end-of-life to dying patients and their families through interventions of pain management, and physical, psychosocial and spiritual well-being, and a dignified death (Bainbridge & Seow 2018:463; Gurdogan et al 2017:180). In their study in Namibia, Powell, Namisango, Gikaara, Moyo, Mwangi-Powell, Gomes & Harding (2014:620) found that most patients desired their end-of-life care to focus on improving their quality of life rather than prolonging it.

End-of-life care focuses on relieving symptoms and improving the quality of life, decreasing patients' length of stay and health care costs (George, Kryworuchko, Hunold, Ouchi, Berman et al 2016:1395). End-of-life care entails making dying patients more comfortable by minimising aggressive life-prolonging treatment and assisting patients and families to adjust fully to the dying and mourning process, and promoting a good death by respecting and observing their wishes and cultural and ethical standards (Tse et al 2016:224; Pal, Kuan, Koh et al 2017:129; George et al 2016:1395).

End-of-life care goals include minimising patients' suffering, taking into consideration their religious and cultural beliefs hence supporting dying with dignity (Tse et al 2016:224). Healthcare professionals working with patients on end-of-life care focus on treatment as well as the psychosocial, emotional and spiritual desires of patients and their families to give dignity (Tse et al 2016:225). For patients to die with dignity, the basics of psychosocial and spiritual care during end-of-life care must focus on patients' fear of death, physical symptoms, their thinking on the general sense of life (Tse et al 2016:229).

End-of-life care in general incorporates all health care assistance during the time before death (Luta, Maessen, Egger et al 2015:2; Decker, Lee & Morphet 2015:70).

2.7.3 Value of quality end-of-life care

Quality end-of-life care refers to carrying out patients' preferences for end-of-life care as this enhances its value before their final days of life (Wang 2016:437). This phase of care is usually observed by the patients' significant others and includes the effective management of the patients and family's physical, emotional, culture, spiritual and ethical needs (Meier, Gallegos, Thomas, Depp, Irwin & Jeste 2016:261). Quality end-of-life care enhances the quality of life for patients and their families through symptom control for patients and general support (Cheung & Chan 2016:9).

Dying a dignified death is an important objective in end-of-life care and providing quality care and good support to dying patients and their families is important in all healthcare settings (Sola, Cortes, Padilla et al 2017:20). A dignified death is described as a death with less invasive treatment and without ineffective, invasive treatment (Guo & Jacelon 2014:935). Dignified care refers to acceptable care given by competent healthcare professionals with relevant knowledge who are trusted by both patient and family (Guo & Jacelon 2014:935).

Creating an environment where patients and their families receive quality end-of-life care will make the patient and family feel appreciated and satisfied (Ranse et al 2016:84). Dying a dignified death is important for the patients, families and healthcare professionals during end-of-life care (Molina, Cortes, Padilla, Caro & Sola 2016:234). A dignified death is a death with no fear and in an environment that is safe and comfortable (Guo & Jacelon 2014:936). For patients on end-of-life care dying with dignity is a necessity and is achieved by relieving and managing symptoms and suffering (Guo & Jacelon 2014:934).

In palliative care, evaluating quality care is important in order to understand patients' requirements and to improve their management (Conrad, Mücke, Marinova, Burghardt et al 2017:604). For evaluation and improvement of care rendered to dying patients, their families and for the support of healthcare professionals to render ideal care during end-of-life care it is crucial to understand present end-of-life care practices of critical care through research (Ranse et al 2016:84). It is important to understand the care of patients in life-threatening diseases and the dying patients in order to provide quality care (Powell et al 2014:620).

Coffey, McCarthy, Weathers, Friedman, Gallo, Ehrenfeld, Chan, Li, Poletti, Zanotti and Molloy (2016:247-257) conducted a study on nurses' knowledge of advance directives and perceived confidence in end-of-life care in Hong Kong, Ireland, Israel, Italy and the USA. The study found that in all five countries older nurses and ones with more professional experience felt more confident managing end-of-life patients' symptoms and comfortable stopping preventive medications at end-of-life. In Israel, for example, there is legislation to regulate medical treatment of terminally ill patients while at the same time balancing respect for life and quality care (Coffey et al 2016:248). In Australasia, Shearer, Rogers, Monterosso et al (2014:249) found that different approaches were used to integrate end-of-life care in the ED. A survey of emergency medicine physicians on the feasibility of screening older ED patients who would benefit from palliative care referral found that most of the ED physicians found it acceptable to screen patients for referral (Ouchi, Block, Schonberg et al 2017:69). However, Ouchi et al (2017:73) found that further research was needed to improve acceptability and determine the appropriate care pathway for patients with palliative care needs. Management through a documented plan of care may enable the delivery of quality end-of-life care (Ranse et al 2014:707).

A successful death is when patients experience a respectable, peaceful death and that is the ultimate goal of end-of-life care (Kongsuwan et al 2016:137). Ensuring comfort is expected in the ED as healthcare professionals are skilled in giving acute analgesia to patients (Shearer et al 2014:254). In Australasia, knowing the treatment for patients, their wishes, managing their symptoms and taking care of the family during end-of-life care has improved in the ED (Decker et al 2015:73). Quality end-of-life care in the ED decreases the distress and anxiety of patients, families and the community. In addition, families are grateful for the care and respect given to patients on end-of-life care (Noome et al 2016:57).

The ever-increasing number of patients needing end-of-life care in the ED has been of growing concern for several years. The 2011 Improving Palliative Care Life in the Intensive Care Unit and Emergency Medicine project (IPAL-EM) identified the required competencies for end-of-life care including recognition of suitable patients and rendering scientifically based care for patients and their families (Wolf et al 2015:678). The IPAL-EM also has guidelines for providing quality end-of-life care in the ED (Wolf et al 2015:678). The 'life- sustaining management alternative' (LSMA) is a patient-centred programme that deals with patients on end-of-life care in the ED with the aim of improving pain and symptom management and provide a comfortable death (Rojas, Schultz, Linsalata, Sumberg, Christensen, Robinson & Rosenberg 2016:205). Once the patient has been enrolled on the LSMA, the patient is given comfort and supportive care relevant to end-of-life care (Rojas et al 2016:205).

2.7.4 Where end-of-life care can be practised

As patients' health condition deteriorates, some visit hospitals or hospice and others remain in the comfort of their own homes (Bausewein et al 2016:13). Home hospice refers to end-of-life care provided at home by doctors, social workers, priests and bereavement counsellors (Bainbridge et al 2016:632). End-of-life care has become synonymous with physical, psychological, social, and spiritual support of patients and currently rendered by a multidisciplinary team (Yates 2017:179). Although many patients would prefer to be nursed in their own home at end of their lives, they are forced to seek help in the ED (Cheung & Chan 2016:9). Dealing with patients on end-of-life care is a daily experience for healthcare professionals working in the ED (Wolf et al 2015:e30).

2.7.5 Consequences of not providing quality end of life care

Offering quality end-of-life care is challenging in the ED (Sola, Cortes, Padilla et al 2017:21). ED healthcare professionals are faced with the stress and challenges of role conflict from life-saving to being expected to render quality end-of-life care (Marck, Weil, Lane et al 2014:368). Emergency care consists of managing acute health problems, making critical decisions under stress and pressure, and with limited time to discuss treatment plans and preferences with patients and their families, which means that the ED culture may not be conducive to palliative care (Cheung & Chan 2016:9). Consequently, the ED environment, work culture, lack of privacy and limited time for discussion with patients and families pose a threat to the proper provision of quality end-of-life care to patients and families, which then leads to dissatisfaction (Sola et al 2017:24). Healthcare professionals know the importance of quality end-of-life care in the ED and have to alter their focus on saving life to providing end-of-life care to patients and their families in order to honour the concept of dignified death in the ED (Molina et al 2015:238). Little or no organisational support for healthcare professionals during end-of-life care exposes them to stress and not being able to cope with their work (Kisorio & Langley 2015:31). When patients are not given enough relevant information to better understand their prognosis and make learned choices, they experience poor quality end-of-life care (Walczak et al 2017:31).

2.7.6 Importance of measuring the quality of end-of-life care

End-of-life care has become a vital component of care in the ED and for ideal care to be rendered healthcare professionals need adequate training to deliver quality end-of-life care in the ED (Tse et al 2016:224: Shearer et al 2014:249). Training in end-of-life care has a positive impact on healthcare professionals' self-confidence and well-being during delivery of end-of-life care (Coffey et al 2016:253).

Quality indicators are performance measures put in place to drive quality improvements in health care (Sinuff, Dodek, You, Barwich et al 2015:1071). Quality indicators are measurable features of care to address precise aspects of care and service level, such as communication and decision making (Sinuff et al 2015:1071). Increased interest in delivering quality end-of-life care has led to developments that measure the quality of end-of-life care (Lendon, Ahluwalia, Wailing, Lorenz et al 2015:904). Measuring quality is an important tool for improving end-of-life care and hospice care hence research is needed on improving the application of quality indicators which are evidence based (Dy Herr, Bernacki, Kamal, Walling, Ersek & Norton 2016:155). Measuring quality care to the dying and their families and identifying necessary interventions for progress are vital for evaluating end-of-life care (Curtis, Downey & Engelberg 2016:1179). Management through a documented plan of care may enable the delivery of quality end-of-life care (Ranse et al 2014:707).

Systematic quality monitoring for specialized palliative care services by means of a minimal set of quality indicators for palliative care study (QPAC) has been recommended to assess the care on a continuous basis and thoroughly improve care at the level of patients and their families (Leemans, Deliens, Van den Block et al 2017:532).The focus would be on measures to institute a patient profile with a shared language within the team which guarantee that complete quality care is offered.

2.8 SUMMARY

This chapter discussed the literature review conducted for the study. The main focus of end-of-life care is to offer comfort to patients at the end of their life. Quality end-of-life care ensures a dignified and good death for patients. End-of-life care in the ED is becoming a reality and EDs are fast becoming providers by default of end-of life care for patients.

Chapter 3 discusses the research design and methodology used in the study.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

Chapter 2 discussed the literature review conducted for the study by the researcher on end-of-life care. This chapter discusses the research design and methodology used to adapt and validate an instrument originally developed for use in ICUs to measure quality end-of-life care in EDs.

3.2 AIM, OBJECTIVES AND STAGES OF THE STUDY

The aim of the study was to adapt and validate an instrument to measure the quality of end-of-life care in emergency departments.

In order to achieve the aim, the objectives of the study were to

- Adapt an instrument used to measure quality end-of-life care in intensive care units for emergency departments.
- Validate the instrument to measure end-of-life care for the emergency departments.

The study was conducted in four stages in order to achieve the objectives as follows:

(1) To adapt the instrument used to measure quality end-of-life care in intensive care units for emergency departments

- Stage 1: Evaluation by expert panel
- Stage 2: Evaluation by target population
- Stage 3: Review by experts

(2) To validate the adapted instrument to measure end-of-life care in emergency departments

- Stage 4: Pilot study

3.3 RESEARCH DESIGN

A research design is a blueprint for conducting a study in a way that is guided, planned, and implemented to achieve accurate results (Burns, Grove & Gray 2013:195). Polit and Beck (2012:58) describe a research design as “the overall plan for addressing a research question, including the specifications for enhancing the integrity of the study”. Research designs help researchers minimize bias and guide the whole process of answering the research questions (Polit & Beck 2017:58; Brink, Van der Walt & Van Rensburg 2012:102).

Researchers select a research design based on the problem and purpose of the study, the type of research questions, and resources available (Burns et al 2013:195; LoBiondo-Wood & Haber 2010:175). The research design guides the selection of the population, sampling, and data collection and analysis (LoBiondo-Wood & Haber 2010:159; Botma, Greeff, Mulaudzi & Wright 2010:108). In this study, the researcher also based the research design on the literature review, theoretical framework, and Clarke, Levy, Randall Curtis, Luce and Nelson’s (2003:2255) ‘ICU Palliative Care Quality Assessment Tool’ for intensive care units.The ‘ICU Palliative Care Quality Assessment Tool’ was based on Clarke et al’s (2003:2255) quality indicators or domains of quality end-of-life care and was developed for and tested in intensive care units.

The researcher considered the selected research design appropriate for the adaptation and validation of an instrument to measure quality EoLC in an ED. The adaptation and validation of an instrument does not necessarily have specific consensual stages, but the process should be guided by the content of the instrument and its targeted population and context (Borsa, Damasio & Bandeira 2012:423). The methodology of this study consisted of four stages, which were adapted from Borsa et al (2012:423) and Beaton, Bombardier, Guillemim and Ferraz (2007:3187). The study was methodological and the researcher collected qualitative and quantitative data in the four stages to adapt and validate the instrument for the ED context to measure quality EoLC.

Methodological research deals with the development and assessment of data-collection instruments, scales and methods (LoBiondo-Wood &Haber 2010:207). Methodological research arises particularly from a theoretical framework as it is used to make an intangible concept measurable (Botma et al 2010:286). In this study, the concept was *quality EoLC in the ED* (LoBiondo-Wood & Haber 2010:158). Methodological designs are also used to improve the validity and reliability of instruments to measure theories and variables (Burns et al 2013:700). Methodological studies assess content and construct validity, as well as the intangible structure of a scale, and evaluate reliability (Burns et al 2013:255). Quantitative research uses structured instruments (Bolarinwa 2015:196).

In cases where an instrument is developed in the absence of an existing suitable instrument, LoBiondo-Wood and Haber (2010:208) recommend the following steps:

- Define the construct/concepts to be measured.
- Formulate the instrument’s items.
- Develop instructions for users and respondents.
- Test the instrument’s reliability and validity.

These steps require a comprehensive literature review to recognize the concepts underlying the construct (LoBiondo-Wood & Haber 2010:208). Ranse, Yates and Coyer (2016:87) maintain that quality end-of-life care must include care delivered according to Clarke et al’s (2003:2258) seven domains. The seven domains are patient and family decision making; communication; continuity of care; emotional and practical support; symptom management and comfort care; spiritual support, and emotional and organizational support. These domains or quality indicators can be used to measure end-of-life care quality.

In the literature review, the researcher identified and selected Clarke et al's (2003:2255) ICU palliative care quality assessment tool', which was guided by Clarke et al's (2003:2255) seven domains. The focus of the study was to adapt and validate the instrument and not to measure the quality of end-of-life care in EDs. Accordingly, the study was conducted in four stages to adapt and validate the tool to measure EoLC in the ED.

3.4 RESEARCH METHODOLOGY

Research methodology is the process or plan for how the study will be conducted and includes the setting, population, sample and sampling, data-collection instrument, and data collection and analysis (Burns et al 2013:264). Research methods are the techniques used to structure a study and to collect and analyse data relevant to the research questions systematically (Polit & Beck 2017:743). The research methods are discussed for the overall study, and then in detail for each stage.

3.4.1 Setting

In this study, the setting or context included EDs in private and public hospitals South Africa. Healthcare professionals in the EDs render care to patients of all ages ranging from newborns to elderly patients on a 24-hour basis, including adult patients with end-of-life care needs.

3.4.2 Population

In research, the population encompasses all elements that meet certain criteria for inclusion in a study (Burns et al 2013:544). A study population refers to a set of individuals having the same characteristics in which the researcher is interested (Polit & Beck 2017:739; LoBiondo-Wood & Haber 2010:221). The target population is the whole population to which the researcher wants to generalise the study findings (Polit & Beck 2017:746; Burns et al 2013:391; Botma et al 2010:124). In this study, the target population referred to healthcare professionals working in EDs.

3.4.3 Sampling

A sample is a group of people or elements that are selected for the study (Burns et al 2013:351). Sampling is the process of selecting a part of the population to represent the total population (Botma et al 2010:124; Polit & Beck 2017:743; Brink et al 2012:145). In most studies, the whole population cannot be investigated hence the purpose of sampling is to increase the efficiency of the study (LoBiondo-Wood & Haber 2010:224).

Purposeful or non-probability sampling is used to select study participants because they understand the research problem and phenomenon under study. Polit and Beck (2017:721) add that in purposive or non-probability sampling, the researcher selects participants based on personal judgement about which ones will be the most informative. The researcher used purposive sampling to select the participants for the study because it allowed her to select participants who were knowledgeable or experts about the research topic (Brink et al 2012:141). In qualitative studies, it is important that data saturation is reached (Brink et al 2012:144). Data saturation is when no new information emerges during data collection (Brink et al 2012:144).

In this study, the researcher selected snowball sampling. Snowball sampling involves the choice of respondents through recommendations by other respondents (Polit & Beck

2017:745). The advantages of snowball sampling are that it is cost effective; researchers spend less time determining suitable respondents, and there is no screening as the population is presumed to be homogeneous (Polit & Beck 2017:492). In this study, the first respondents were purposively identified and asked to identify other experts in the field of emergency care who met the inclusion criteria. The researcher then contacted potential respondents (nurses and doctors) until the sample met the proposed number to participate (Borsa et al 2012:423; Cornally et al 2015:247).

3.4.4 Data-collection instrument

Data collection is the precise, systematic gathering of information relevant to the research purpose or specific objectives of a study (Burns et al 2013:41). A data-collection instrument is a tool for collecting or recording data about a specific topic and related to the objectives of the study (Bolarinwa 2015:196). A data-collection instrument should be based on the research design and research question (Botma et al 2010:245). Therefore the researcher conducted a literature review to identify an instrument to measure the quality of EoLC in the ED. In the absence of a comprehensive instrument for the ED context, the 'ICU Palliative Care Quality Assessment Tool' (Levy et al 2003) that measures quality EoLC in the ICU, was selected for adaptation and validation in this study. The researcher obtained consent from one of the original authors to use, adapt and validate the instrument for the ED context (see Annexure A1).

Clarke et al (2003:2256) identified the need for improving EoLC in ICUs and developed seven quality indicators or domains for EoLC in ICUs. Healthcare professionals should carry out the items in each domain to improve quality EoLC in an ICU (Ranse et al 2014:699). The seven domains are patient and family decision making; communication; continuity of care; emotional and practical support; symptom management and comfort care; spiritual support, and emotional and organizational support. These domains or quality indicators can be used to measure end-of-life care quality.

In cases where an instrument is developed in the absence of an existing suitable instrument, LoBiondo-Wood and Haber (2010:208) recommend the following steps:

- Define the construct/concepts to be measured.
- Formulate the instrument's items.
- Develop instructions for users and respondents.
- Test the instrument's reliability and validity.

These steps require a comprehensive literature review to recognize the concepts underlying the construct (LoBiondo-Wood & Haber 2010:208). In the literature review, the researcher identified and selected Clarke et al's (2003:2255) 'ICU palliative care quality assessment tool', which was guided by Clarke et al's (2003:2255) seven domains. The focus of the study was to adapt and validate the instrument and not to measure the quality of end-of-life care in EDs. Accordingly, the study was conducted in four stages to adapt and validate the tool to measure EoLC in the ED.

The 'ICU Palliative Care Quality Assessment Tool' was tested with critical care nurses and physicians working in ICUs in the United States and Canada to compare their ratings of the quality and intensity of palliative care in the ICUs (Ho, Engelberg,Randall Curtis, Nelson, Luce, Ray & Levy 2011:776; Luta et al 2015:1). The first section of the instrument includes a cover page, which covers information on the type of institution, type of unit and the date the instrument is completed. The second section contains instructions followed by 61quality indicators arranged according to the seven domains of palliative care. Respondents have to rate each item on a 10-point Likert scale. Respondents are asked to circle the number that corresponds to the 'best answer choice'.

3.4.5 Data collection

Data collection is the procedure of collecting relevant information for the purpose of the study in an unbiased and organized way (Polit & Beck 2017:725; LoBiondo-Wood & Haber 2010:269).

In stages 1 to 3 of data collection, an email was sent to the respondents to invite them to participate. The study was explained in a respondent information leaflet (see Annexures B1, C1 and E1). Once respondents volunteered to participate, a demographic information sheet (in Microsoft Word format) (see Annexure B2) and the original 'ICU Palliative Care Quality Assessment Tool' (in PDF format) were emailed to them. In addition, the respondents received the items of the instrument in an electronic survey management system, Qualtrics, or in a Microsoft Word document, which allowed them to give feedback (see Annexure B4). The respondents were asked to give feedback on the instructions to respondents, the layout of the instrument, the 10-point Likert scale, and each item.

In terms of the items, the respondents were asked to independently rate the relevance of each of the 61 items. After that the respondents were asked to comment on the content clarity (wording) of each item one (Borsa et al 2012:425). The respondents were given an opportunity to add additional items to the instrument that they considered relevant to the provision of quality end-of-life in the ED (Ranse et al 2014:699). Text boxes were provided for comments or rephrasing of the items (Lavoie, Cossette, & Pepin 2016:63).

The panel of experts was given a period of three weeks to respond. After three weeks a reminder email was sent to them. Four rounds were conducted until100% of the experts agreed on all the items. Detailed procedures in the stages follow.

3.4.6 Data analysis

Data analysis is the systematic organization and synthesis of data to establish order, structure and meaning to qualitative data collected (Polit & Beck 2017:725; Botma et al 2010:220). Data analysis is a process that reduces, organizes, and gives meaning to data (Burns et al 2013:538). Data analysis entails categorising, ordering, manipulating, summarising and describing the data in meaningful terms (Brink et al 2012:170). Polit and Beck (2017:725) add that data analysis is the logical organisation and production of research data to answer the research question. Descriptive statistics use numerical values to describe, analyse and summarise data in a meaningful way for data interpretation (Polit & Beck 2017:726; LoBiondo-Wood &Haber, 2010:577).

In all the stages of the study, descriptive data analysis was used to summarise the respondents' demographic characteristics. Data analysis included frequencies, means, standard deviation deviations and ranges (Burns et al 2013:538).The Item Context Validity Index (I-CVI) was used to evaluate the extent of expert agreement on relevance of items (Van Lancker, Beeckman, Verhaeghe, Noortgate, Grypdonck, & Hecke (2016:39).This index has the advantage of providing an item-level score (Pierce et al 2015:1566; Chover-Sierra, Martínez-Sabater & Lapeña-Moñux 2017:3). An I-CVI of more than 80% in a panel of 10 or more respondents is recommended (Pierce et al 2016:1568).

Objective 1: To adapt the instrument used to measure quality end-of-life care in intensive care units for the emergency department (ED)

3.4.7 Stage1: Evaluation by expert panel

Stage 1 consisted of four rounds and the research methods for each round are briefly described.

3.4.7.1 Population and sampling

Experts are respondents with knowledge on the subject, clinical experience and able to provide detailed information on the construct, purpose and intended use of the instrument (Peirce et al 2016:1568). Regarding content validity, Peirce et al (2016:1569) recommend that a panel of experts determine the relevance of the items of an instrument. Moreover, the members of the expert panel should add items considered relevant to the provision of quality end-of-life in the emergency department (Ranse et al 2014:699). A panel of five to six experts is normally enough to minimise the risk chance of agreement (Cornally et al 2016:247).

Purposive snowball sampling was used to identify experts (medical doctors and registered nurses) working in EDs. To be included in the study, the expert healthcare professionals had to:

- Work in an ED in South Africa.
- Have an additional qualification in emergency medicine/emergency nursing.
- Have at least two years' experience in the ED.
- Verbalize a self-reported interest in end-of-life care (EoLC) in the ED.

3.4.7.2 Data collection

An e-mail was sent to the respondents to invite them to participate. The study was explained in a participant information leaflet. Once the respondents volunteered to participate and signed informed consent, a demographic information sheet was e-mailed to them as well as the instrument on which the corrections received from one round was incorporated (see Annexures B5, B8, B10 and B12). The researcher had received no responses after three weeks. Consequently, the researcher contacted the respondents telephonically to enquire about the lack of participation. The respondents then requested a MicroSoft Word document, as it was too time consuming to complete Qualtrics and they struggled to gain a comprehensive overview of the instrument. The instrument was converted to a Microsoft Word document and re-sent to all the respondents. Subsequently a reminder was sent weekly. The four rounds were completed over three months until the I-CVI was 100% for all the items, which means consensus was reached.

3.4.7.3 Data analysis

Data from the four rounds were summarised in a feedback sheet (see Annexures B5, B8, B10 and B12). Data analysis was done using descriptive analysis and included frequencies, means, standard deviation and ranges (Burns etal 2013:538). were analysed as explained in (Section 3.4.6).

In all the stages of the study, descriptive data analysis was used to summarise the respondents' demographic characteristics. Data analysis included frequencies, means, standard deviation deviations and ranges (Burns et al 2013:538). The Item Context Validity Index (I-CVI) was used to evaluate the extent of expert agreement on relevance of items (Van Lancker et al 2015:39). This index has the advantage of providing an item-level score (Pierce et al 2015:1566; Chover-Sierra, Martínez-Sabater & Lapeña-Moñux 2017:3). An I-CVI of more than 80% in a panel of 10 or more respondents is recommended (Peirce et al 2016:156).

3.4.8 Stage 2: Evaluation by target population

The aim of this stage was for the target population to evaluate the instructions and layout of the instrument and Likert scale used as well as the individual items (Borsa et al 2012:426).

3.4.8.1 Population and sampling

The respondents were drawn from the target population for which the instrument was adapted, namely healthcare professionals working in the ED (Sousa & Rojjanasrirat 2010:271; Beaton et al 2003:3189). Purposive snowball sampling was used to identify the respondents.

To be included in the study, the respondents had to be healthcare professionals (doctors and registered nurses) who:

- Worked in EDs in South Africa.
- Had a minimum of two years' experience in the ED.
- Had experience in the management of patients with EoLC needs in the ED.
- Had an additional qualification in emergency medicine or emergency nursing
- Did not participate in Stage 1.

3.4.8.2 Data collection

The researcher invited the respondents to evaluate the revised instrument (from Stage 1) for measuring the quality of EoLC in the ED (Ranse et al 2014:699). The researcher e-mailed the participant information leaflet to the respondents, outlining the aim of the study as well as general information and were asked to sign the consent form (see Annexure B1). Once the respondents volunteered to participate, a revised hard copy of the instrument was distributed to Stage 2 respondents (see Annexure C3). They were asked to comment on the feedback instrument provided and/or make comments on the hard copy provided.

3.4.8.3 Data analysis

Data were analysed in the same way as in Stage 1 (see Section 3.4.6.3). Data analysis was done using descriptive analysis and included frequencies, means, standard deviation deviations and ranges (Burns et al 2013:538). After the analysis, the instrument was updated with minimal changes for distribution in Stage 3.

3.4.9 Stage 3: Evaluation by experts

The aim of this stage was for the experts who developed the 'ICU Palliative Care Quality Assessment Tool' to evaluate the adapted instrument. Borsa et al (2012:427) emphasise that in order to avoid bias in this stage, the suggested changes should be done with the assistance of the expert(s) who developed the original instrument. A further reason was to get advice before attempting validation of the adapted instrument in Stage 4 (Beaton et al 2000:3189).

3.4.9.1 Population and sampling

The inclusion criterion in Stage 3 was to be one of the original authors of the 'ICU Palliative Care Quality Assessment Tool'. Accordingly, the researcher invited the author, Randall Curtis. However, the author could not participate owing to work-related responsibilities**.** In the absence of the original authors the researcher opted to use purposive sampling and asked one international and one national expert in EoLC in the ED to participate, namely a doctor (national) and a registered nurse (international).

3.4.9.2 Data collection

The same data-collection procedures were used as in Stage 2. The researcher invited the respondents to evaluate the refined instrument (from Stage 1 and 2) for measuring the quality of EoLC in the ED (Ranse et al 2014:699). The respondents received a leaflet outlining the aim of the study as well as general information and were asked to sign the consent form (see Annexure B1). After the respondents’ suggestions had been incorporated, the instrument was sent to both respondents for final approval (see Annexure E2 adapted instrument).

3.4.9.3 Data analysis

No data analysis was necessary as the adapted instrument was ready to be pilot tested and validated.

Objective 2: Validation of adapted instrument

3.4.10 Stage 4: Pilot study

In order to determine whether a new instrument is ready for application, a pilot study must be carried out (Peirce et al 2016:1567; Borsa et al 2012:426). A pilot study was conducted to test the ‘End-of-Life Care Quality Assessment in the Emergency Department’ instrument with a group of respondents (doctors, registered nurses and emergency care practitioners) in the ED to review their understanding of the instrument and the relevance of the items (Chover-Sierra et al 2017:3; Beaton et al 2000:3189).

For a pilot study, Tsang, Royse and Terkawi (2017:S87) recommend a respondent-to-item ratio of 5:1 to 30:1 and Hertel-Joergensen, Abrahamsen and Jensen (2018:41-48) recommend a minimum of 200 respondents. For the purpose of this study, the researcher aimed for a ratio of 5:1, with a minimum of 305 respondents (Sousa & Rojjanasrirat 2010:272).

3.4.10.1 Population and sampling

Purposive snowball sampling was used to collect data from healthcare professionals working in the ED. The respondents were asked to participate in their personal capacity. The researcher and supervisors contacted the respondents and then asked them to forward the instrument to potential respondents who met the inclusion criteria.

To be included in this stage of the study, the respondents had to be healthcare professionals (doctors, registered nurses and emergency care practitioners) who:

- Were working in EDs in South Africa.
- Had a minimum of two years' experience in the ED.
- Had experience in the management of patients with EoLC needs in the ED.
- Did not participate in the adaptation stages (Stages 1 to 3).

3.4.10.2 Data collection

The instrument was distributed in hard copy as well as electronically. A total of 650 hard copies were distributed by hand to various EDs. In addition, the instrument was e-mailed to 31 unit managers of EDs as well as five emergency care practitioners and six doctors who were asked to distribute the instrument to doctors, registered nurses and emergency care practitioners who met the inclusion criteria.

3.4.10.3 Data analysis

Descriptive statistics were again used to describe the sample. Cronbach’s alpha value was applied to determine the internal consistency within the different domains and sub-domains of the instrument (Chover-Sierra et al 2017:6; Polit & Beck 2017:725;) (see Annexure E.2) A Cronbach’s alpha value of 0.7 and above indicated a good level of internal consistency and a value of less than 0.7 indicated a low level of internal consistency (Burjales-Marti, Rigol-Cuadra, Anguiano-Carrasco, Martorell-Poveda et al 2018:19; Darrel & Mallery 2003).

The relationship between the Likert scale scores of the doctors and registered nurses were investigated. The scores on the 10-point Likert scale given by the doctors and registered nurses for the perceived quality of end-of-life care delivered by the team was categorised into three categories, namely poor (0 to 3), moderate (4 to 7), and excellent (> 7). The scores in the different domains were compared using Fischer’s exact test in 3 by 3 contingency tables. Significance was determined at a level of P smaller than 0.05. The number of emergency care practitioners was inadequate to apply Fischer’s exact test (n=14).

3.5 RIGOUR

Rigour refers to the strategies implemented by the researcher to improve the accuracy of the findings (Burns et al 2013:690; LoBiondo-Wood & Haber 2010:159). The quality of research and research instruments is determined by their validity and reliability. Validity refers to the extent to which an empirical measure reflects the real meaning of the concept under consideration (Polit & Beck 2017:336; Ridwan, Ali, Mohamed, Adam & El Fadil 2016:2116). The validity of a data-collection instrument refers to its accuracy and trustworthiness in research (Flinkman, Leino-Kilpi, Numminen, Jeon, Kuokkanen & Meretoja 2016:1038). Validity refers to the degree to which an instrument measures what it is intended to measure (Brink, Van der Walt & Van Rensburg 2012:109). In this study, face and content validity were determined as well as the internal consistency of the domains of EoLC in the ED. Face validity involves looking at the operational indicators of a concept and deciding whether or not, on the face of it, indicators make sense (Polit & Beck 2017:336). Face validity entails reviewing items of instruments to determine whether the test is a valid measure of the concepts being investigated (Bolarinwa 2015:196**.** In this study, face validity also referred to the readability, clarity and relevance of the items.

Content validity refers to the degree to which an instrument adequately covers the construct being measured (Polit & Beck 2017:336). To ensure content validity, the instrument should measure what it is intended to measure (Botma et al 2010:174; Burns & Grove 2012:377). Content validity refers to the relevance of items and the extent to which the instrument fully measures or assesses the construct of concern, in this case quality EoLC (Bolarinwa 2015:196; Polit & Beck 2017:724). Content validity is achieved when an instrument has appropriate content for measuring a complex concept, or construct. Furthermore, content validity concerns the degree to which an instrument has an appropriate sample of items for the construct being measured and adequately covers the construct domain (Polit & Beck 2017:336). Face and content validity are closely related and define whether an instrument assesses that the content covered is relevant, significant, non-redundant, and clear (Bausewein, Daveson, Currow, Downing, Deliens et al 2016:16). Context validation includes consultations with experts, and is concerned with relevance and comprehensiveness (Polit &Beck 2017:310). Relevance refers to whether the items of the instrument are relevant to the target population (Polit & Beck 2017:310). Comprehensiveness determines whether the full complexity of the construct under investigation is covered in the instrument (Polit & Beck 2017:310).

Reliability of the data-collection instrument refers to the consistency with which it measures the target attributes (Polit & Beck 2017:331). Construct validity and different types of reliability fell outside the scope of the study and were therefore not considered.

Table 3.1 summarises the strategies used to develop and to ensure the validity of the adapted and validated instrument for the ED.

Table 3.1 Summary of strategies followed to increase validity

Type of validity	Strategy by stage		
	ICU Palliative Care Quality Assessment instrument	**Stages 1 and 3**	**Stages 2 and 4**
Face	Review by experts	Review of the instrument for understanding and relevance by experts familiar with research topic	Review of the instrument by target population
Content	Item generation through a comprehensive literature review Review of the items by critical care nurse specialists and physicians	Review by experts	Review by target population

Table 3.1 summarises the strategies used for validation of the 'End-of-life Care Quality Assessment in the Emergency Department' instrument. Clarke, Levy, Randall Curtis, Luce and Nelson (2003:2255) developed the 'ICU Palliative Care Quality Assessment Tool' for intensive care units. The instrument was based on Clarke et al's (2003:2255) quality indicators or domains of quality end-of-life care and was developed for and tested in intensive care units.

According to Ranse et al (2016:87), quality end-of-life care must include care delivered according to Clarke et al's (2003:2258) seven domains. The researcher wished to adapt and validate an instrument to measure the quality of end-of-life care in emergency departments. Accordingly, the researcher selected Clarke et al's (2003) instrument based on Clarke et al's (2003) seven domains or quality indicators. The validity of the 'End-of-life Care Quality Assessment Tool for the Emergency Department' was determined in four stages in order to meet the study objectives.

3.6 SUMMARY

This chapter discussed the research design and the methodology of the study in order to adapt and validate an instrument to measure the quality of end-of-life care in an ED. The four stages of the study were described in detail as well as the strategies to ensure rigour and validity.

Chapter 4 presents and discusses the findings of the study.

CHAPTER 5
DATA COLLECTION, ADAPTATION, AND RESULTS

5.1 INTRODUCTION

Chapter 4 presented the results and discussed the findings of the study. This chapter briefly discusses the conclusions and limitations of the study and the implications for practice and makes recommendations for further research.

5.2 AIM AND OBJECTIVES OF THE STUDY

The aim of the study was to adapt and validate the ‘ICU Palliative Care Quality Assessment Tool’ to measure the quality of end-of-life care in emergency departments. In order to achieve the aim, the objectives of the study were to:

- Adapt an instrument used to measure quality end-of-life care in intensive care units for emergency departments.
- Validate the instrument to measure end-of-life care for emergency departments.

The study was conducted in four stages to achieve the objectives.

5.3 CONCLUSIONS

In the absence of a comprehensive instrument to measure quality end-of-life care in the ED, the researcher conducted this study. The four-phase study resulted in the adaptation and validation of the ‘ICU Palliative Care Quality Assessment Tool’ for ICU instrument to measure quality EoLC in the ED (see Annexure B.3 and F). Data was collected from 1 June 2018 to 30 November 2018.

Objective 1: Adaptation of an instrument

5.3.1 Stage 1

In stage 1, 13 respondents (8 registered nurses and 5 doctors) participated in round 1 and 7 respondents (5 registered nurses and 2 doctors) participated in round 2, 3 and 4. Based on the respondents' feedback, the researcher added a demographic information section, and 16 items were rephrased to suit the ED and improve understanding. For example, the word "clinicians" was replaced with "members of the healthcare team". A 10-point Likert scale was maintained as it allows increased accuracy in measurement.
In Round 4 consensus (I-CVI = 100%) was reached and Stage 2 was commenced.

5.3.2 Stage 2

In Stage 2, 33 respondents (14 doctors and 19 registered nurses) reviewed the drafted instrument. The respondents found the instructions, the layout and all the items relevant and no changes were made to the instrument. Consensus (I-CVI = 100%) was reached on all the items consequently Stage 3 was commenced.

5.3.3 Stage 3

Initially, the aim of this stage was for the experts who had developed the 'ICU Palliative Care Quality Assessment Tool' to evaluate the adapted instrument. However, none of the original authors of the instrument could participate. Consequently, in the absence of the original authors, the researcher asked one international and one national expert in EoLC in the ED to participate, namely a doctor (national) and a registered nurse (international). The respondents were asked to give feedback on the instructions, layout and the Likert scale and items in the adapted instrument, now referred to as 'End-of-Life Care Quality Assessment in the Emergency Department' instrument. Consensus was reached that the layout and Likert scale were relevant.

Based on the respondents' feedback, the word "perception" was added to the instructions about the scoring of quality of end-of-life care; the concept "end-of-life care" was clarified by adding Razmaria's (2016:115) definition of end-of-life care since the focus of the entire instrument was on quality end-of-life care in the ED, and emergency care practitioners were added to the healthcare professionals who participated in completing the survey as they worked in the ED, specifically in the private sector.

Once consensus was reached, the instrument 'End-of-Life Care Quality Assessment in the Emergency Department' was finalised for distribution in Stage 4.

Objective 2: To validate the adapted instrument to measure end-of-life care in emergency departments

5.3.4 Stage 4

In Stage 4, a pilot study was done to validate the 'Quality End-of-life Care Assessment in Emergency Departments' instrument, now referred to as the 'Perception of Quality End-of--Life Care in the Emergency Department' (P-QEoLCED). The researcher selected 315 respondents for the pilot study. The respondents consisted of doctors (n=55), registered nurses (n=246), and emergency care practitioners (n=14) working in both the private and public sectors in EDs in South Africa. The aim of Stage 4 was to validate the instrument adapted from Stages 1 to 3 for the ED context.

The Cronbach's alpha values for all the domains and sub-domains, except for one sub-domain of Continuity of care, were above 0.70, which indicated a good internal consistency.

5.4 LIMITATIONS

The researcher identified the following limitations in the study:

- In Stage 1, 13 respondents participated in round 1, but only 7 (53.8%) continued in rounds 2 to 4.
- Ideally, the original authors of the 'ICU Palliative Care Quality Assessment Tool' should have participated in Stage 3, but were unable to because of work responsibilities.
- Emergency care practitioners were not involved in stages 1 to 3.

- A test-re-test analysis to obtain more evidence about reliability was not done.

5.5 IMPLICATIONS FOR PRACTICE

The implications for nursing practice are:

- A valid instrument 'Perception of Quality End-of--Life Care in the Emergency Department' (P-QEoLCED) is available to measure perceived quality end-of-life in the ED.
- Healthcare professionals should initiate end-of-life care in the ED
- Healthcare professionals should monitor and evaluate the perceived quality end-of-life in the ED
- Healthcare professionals should strive to improve end-of-life care provided in the ED

Implications for management:

- Managers will be able to use the instrument to improve the practice of EoLC in the ED.
- Measuring the perceptions of healthcare professionals, patients and their families about the end-of-life care provided should be included into policies of EDs

Implications for nursing education:

- The instrument may be used to raise awareness of the domains of EoLC in the ED.
- Nurse educators should include the instrument in end-of-life care curricula as a guide

5.6 FURTHER RESEARCH

Based on the findings, the researcher makes the following recommendations for further research:

- An investigation into the validity and reliability of the P-QEoLCED instrument
- A qualitative exploration of healthcare professionals' perceptions of the reliability and use of the P-QEoLCED
- Healthcare professionals' perceptions of quality of EoLC in EDs in both the private and public sector
- Families' and patients' expectations and perceptions of quality end-of-life care in the ED – in private and public hospitals
- Healthcare professionals' perceptions of barriers and challenges to providing quality end-of-life care in the ED
- Paramedics' and emergency healthcare professionals' experiences of providing quality end-of-life care in the ED
- The role of shared decision making in the provision of quality end-of-life care in the emergency department
- Nurses' lived experience of caring for dying patients in the emergency department
- Healthcare professionals' views on practical changes in emergency departments to improve and 'ease' the provision and experience of EoLC.

Researchers embarking on similar studies should take into account that the data-collection process is time consuming. In the case of this study, it took six months.

5.7 CONCLUSION

Although most patients at the end of their lives prefer to be nursed and die at home, many of them seek help from healthcare professionals in the emergency department before death occurs and end up dying in the ED (Cheung & Chan 2016:9). The researcher observed that initiating and delivering end-of-life care in the EDs today is fast becoming a reality as EDs are increasingly becoming the default health professionals for patients with end-of-life care needs (Cheung & Chan 2016:9; Bradley, Burney & Hughes 2013:334).

In the ED, healthcare professionals' main aim is to provide resuscitative care to save and prolong the lives of critically ill/injured patients and prevent death (Tse et al 2016:224). In reality patients die in the ED, whether expected or unexpected. Moreover, patients in need of end-of-life care require a different approach from the aggressive lifesaving approach usually practised in the ED (George, Phillips, Zaurova et al 2016:108). The ED is busy, chaotic and overcrowded and healthcare professionals work under pressure which leaves little time to practise holistic end-of-life care. The limited time and the fact that many of the healthcare professionals are not trained to provide end-of-life care make them feel incompetent to deliver quality end-of-life care in the ED (Ranse, Yates & Coyer 2016:84). Consequently, dying with dignity in an environment that is noisy and chaotic, and offers little privacy is not easy to accomplish (Molina, Cortes, Padilla, Caro & Sola 2016:233).

The quality of end-of-life care delivered in the ED is currently not measured. Measuring the quality of end-of-life care in all contexts is vital to ensure that a high standard of care is maintained as it may influence the patients' and their families' quality of life and outcome (Cornally et al 2015:245). This motivated the researcher to adapt the 'ICU Palliative Care Quality Assessment Tool' for the ED context. In Stage 4 of the study the P-QEoLCED was piloted for validation. The P-QEoLCED was found valid and can be used to assess quality EoLC in the ED context.

Dr Cicely Saunders said, “You matter because you are you, and you matter to the last moment of your life” and “how people die remains in the memory of those who live on”. The researcher hopes that through this study and the development of the P-QEoLCED instrument healthcare professionals in the ED will be enabled to provide the best quality end-of-life care they can in the circumstances and that the families of the patients who received that care may be comforted with the care provided.

CHAPTER 4

DATA COLLECTION, ADAPTATION, AND RESULTS

4.1 INTRODUCTION

Chapter 3 described the research design and methodology used to adapt and validate an instrument originally developed for use in ICUs to measure quality end-of-life care in EDs. This chapter presents the results of the adaptation and validation of an instrument to measure quality end-of-life care in the emergency department (ED). The study was conducted in four stages to achieve the aim and objectives. The results are discussed with reference to related literature.

4.2 AIM, OBJECTIVES AND STAGES OF THE STUDY

The aim of the study was to adapt and validate an instrument to measure the quality of end-of-life care in emergency departments. In order to achieve the aim, the objectives of the study were to:

- Adapt an instrument used to measure quality end-of-life care in intensive care units for emergency departments.
- Validate the instrument to measure end-of-life care for the emergency departments.

In order to achieve the objectives, the study was conducted in four stages as follows:

(1) To adapt the instrument used to measure quality end-of-life care in intensive care units for emergency departments

- Stage 1: Evaluation by expert panel
- Stage 2: Evaluation by target population
- Stage 3: Review by experts

(2) To validate the adapted instrument to measure end-of-life care in emergency departments

- Stage 4: Pilot study

Note: No discussion of the individual items is provided as the aim of the study was to adapt and validate the instrument to measure the quality of end-of-life care (EoLC) in EDs. The instrument to be adapted and validated was Clarke et al's (2003) 'ICU Palliative Care Quality Assessment Tool' developed for ICUs. The instrument was based on Clarke et al's (2003:2255) quality indicators or domains of quality end-of-life care, namely 1) patient- and family-centred decision making, 2) communication, 3) continuity of care, 4) emotional and practical support, 5) symptom management and comfort care, 6) spiritual support, and 7) emotional and organisational support for healthcare workers, and these domains guided this study. The literature review discussed in chapter 2 provided further information on the instrument.

4.3 TIMEFRAME

Data was collected from 1 June 2018 to 30 November 2018 (see Table 4.1).

Table 4.1 Timeframe for data collection, 2018

	Stage 1	Stage 2	Stage 3	Stage 4
Timeframe	01 June to 28 August	06 September to 15 October	18 to 21 October	23 October to 30 November

The data was collected in four stages over a period of six months. Stages 1 to 3 addressed Objective 1 and Stage 4 addressed Objective 2.

Stages 1 to 3 data collection and results are presented in terms of:

- Respondents
- Inputs on instructions, layout and Likert scale

- Inputs on items
- Discussion of related literature

Stage 4 data collection and results are presented in terms of:

- Respondents
- Internal consistency of the domains of the instrument
- Overall assessment of quality

Objective 1: Adaptation of instrument

4.4 STAGE 1: EVALUATION BY EXPERT PANEL

A total of 21 respondents (12 doctors and 9 nurses) were invited for Stage 1. The respondents met the inclusion criteria of working in an ED in South Africa; having an additional qualification in emergency medicine/emergency nursing; at least two years' experience in the ED, and expressing a self-reported interest in end-of-life care (EoLC) in the ED.

The researcher found no experts in South Africa who had an additional qualification in EoLC in the ED, possibly because there are no formal courses or programmes available for this setting. One expert was identified who was enrolled for a postgraduate diploma in Palliative Care, which she completed in November 2018. The diploma programme was not specifically related to EoLC in the ED, but on palliative care in general.

Four rounds were conducted in Stage 1. In Stage 1, 13 respondents (8 registered nurses and 5 doctors) participated in round 1 and 7 respondents (5 registered nurses and 2 doctors) participated in round 2. These 7 respondents participated in rounds 3 and 4. Table 4.2 summarises the demographic details of the respondents in rounds 1 to 4 in Stage 1.

Table 4.2 Stage 1: Respondents' demographic information

Variable	Round 1	Round 2	Round 3	Round 4
Number of respondents	13	7	7	7
Gender				
Male	5	2	2	2
Female	8	5	5	5
Professional qualification				
Nurse	8	5	5	5
Doctor	5	2	2	2
Additional qualification				
Emergency nursing				
Emergency medicine	8	5	5	5
Experience (ED)				
Range (in years)	10 to 25	10 to 25	10 to 25	10 to 25
Mean	18	20	20	20
Experience in instrument development	4	4	4	4
Training (End-of-life care)	Nil	Nil	Nil	Nil

When the researcher received no feedback from the respondents to the electronic document (e-mail), she contacted them telephonically. The respondents then explained that the electronic platform tool was too long to complete as they wished to see 'the big picture' and move easily between the items and sections. Furthermore, the respondents indicated that they wanted to go through the instrument, take time to reflect, and make handwritten comments on the document itself. The researcher is of the opinion that the electronic distribution of the instrument may have contributed to the withdrawal of some respondents.

Discussion: The number recommended for expert panel participation was maintained within the acceptable range of six (6) to eight (8) participants (Borsa et al 2012:423; Cornally et al 2015:247). As indicated in table 4.2, 6 respondents did not participate to the end of stage 1 for unknown reasons. The selection of suitable experts was important to confirm that content validity was sufficiently assessed (Tsang et al 2017:S86). The respondents for stage 1 included nurses and doctors working in the ED in South Africa. The experts were a panel of respondents who had clinical experience relating to EoLC in the ED and were therefore able to provide inputs on the items to ensure the content validity of the instrument (Tsang et al 2017:S87). In addition, four experts had expertise in instrument development (Pierce et al 2016:1658). The researcher identified no experts with training in EoLC in the ED.

Emergency care practitioners were not included in Stage 1 as these healthcare professionals were only identified as important role players by the experts during Stage 3.

4.4.1 Inputs on instructions, layout and Likert scale

The respondents were asked to give feedback on the instructions, layout and the 10-point Likert scale used in the instrument. Table 4.3 summarises the inputs from Stage 1.

Table 4.3 Stage 1: Summary of inputs on instructions, layout and Likert scale

Rounds	Instructions	Layout	Likert scale
Round 1 (n=13)	Include demographic information. Replace ‘ICU’ with ‘ED’ Define ‘clinicians’. Define ‘physicians’. Replace palliative care with end-of-life care.	Acceptable (100%)	Acceptable (100%)
Round 2 (n=7)	Include setting ‘private’ and ‘public’ in the demographic section. Use cross (x) rather than circling the selected option.	Acceptable (100%)	Acceptable (100%)

Rounds	Instructions	Layout	Likert scale
Round 3 (n=7)	Add 'public' and 'private' sector in demographic information section.*	No comments	Use a 5-point Likert scale
Round 4 (n=7)	No comments	No comments	No comments
* There was an oversight of the researcher's to add this variable.			

All the feedback received from the respondents is included in Annexures D4, D6, D8, and D10. All the comments except changing the Likert scale were accepted.

In round 4, consensus (I-CVI 100%) was reached and no comments were made on the instructions, layout and Likert scale (see Annexure B12).

Discussion: In terms of instructions, the respondents suggested the following: replacing 'ICU' with 'ED' to clarify the context for which the instrument has been adapted; including a 'Demographic information' section in order to describe and categorise respondents, and adding 'public' and 'private' hospitals as South Africa has both these service delivery sectors. South Africa is unique as there is currently a pluralistic health care system with separate public and private sectors and third- and first-world health conditions in the population (Rowe & Moodley 2013). The respondents also suggested using a cross (X) consistently to indicate the options on the instrument and not circling options.

According to the respondents, the layout and format of the instrument were relevant, user-friendly, and easy to understand. The instrument consists of seven pages, which is within the limits of a maximum of 12 pages (Bourque & Fielder 2003:6). A well formatted instrument will assist respondents to complete it within a limited time. In this instrument, shading boxes were used to indicate the different sections, which is one way to maximise the clarity and order of an instrument (Bourque & Fielder 2011:2).

A 10-point Likert scale was used in the original instrument, which remained unchanged despite the recommendations from five respondents to use a 5-point Likert scale. A 10-point Likert scale allows for increased accuracy in measurement (Joshi, Kale, Chandel &

Pal 2015:398; Nemoto & Beglar 2013:5). In this study, the items on the Likert scale ranged from undesirable on the left to positive on the right, which is recommended (Hartley 2013:84; Nemoto & Beglar 2013:5).

4.4.2 Inputs on items

A total of 45 items remained unchanged and 16 items were rephrased (see Table 4.4 and Table 4.5). Table 4.5 presents examples of items that were rephrased. All rephrased items were included in the annexures. (See Annexure B5 for Round 1, Annexure B8 for Round 2, and Annexure B10 for Round 3.)

Table 4.4 Stage 1: Summary of items rephrased according to respondents' suggestions

Rounds	Sections	Items rephrased
Round 1	A. Demographic information	Nil
	B. Communication within the team **and with** patients **and** families	11
	C. Patient- and family-centred decision making	13, 20
	D. Continuity of care	26
	E. Emotional and practical support **for patients and families?**	29
	F. Symptom management and comfort care	Nil
	G. Spiritual support for patients and families	Nil
	H. Emotional and organisational support of the healthcare team	47, 50, 51
	I. Overall assessment of the quality of end-of-life care by doctors and nurses and emergency care practitioners	53 to 55, 57, 59, 60
Round 2	A Demographic information	Nil
Rounds	**Sections**	**Items rephrased**
	B. Communication within the team **and with** patients and families	8
	C. Patient- and family-centred decision making	20
	D. Continuity of care	24
	E. Emotional and practical support for patients and families	Nil
	F. Symptom management and comfort care	Nil

	G. Spiritual support for patients and families	Nil
	H. Emotional and organisational support of the healthcare team	46
	I. Overall assessment of quality of end-of life care provided by doctors, nurses and emergency care practitioners.	Nil
Round 3	A Demographic information	Nil
	B Communication within the team and with patients and families	1, 3, 5
	C. Patient- and family-centred decision making	11, 15
	D. Continuity of care	23, 27
	E. Emotional and practical support for patients and families	Nil
	F. Symptom management and comfort care	41
	G. Spiritual support for patients and families	45
	H. Emotional and organisational support of the healthcare team	46, 47
	I. Overall assessment of quality of end-of-life care provided by doctors, nurses and emergency care practitioners	53 to 64
Round 4	No items removed or rephrased (CVI 100%)	

For example, item 24 in the original instrument ‘ICU Palliative Care Quality Assessment Tool ’(see Annexure B3) stated, “Forgo life-sustaining treatments in a way that ensures the patient’s and family’s preferences are respected”. The respondents indicated that the term “forgo” was not familiar in the South African setting and suggested that the word be replaced with ‘withhold’, which was done (see Annexure D4,item 24). Table 4.5 lists two more examples.

Table 4.5 Stage 1: Examples of rephrased items

Item	Original instrument*	Rephrased
36	Maximise privacy for the dying patient and family	Ensure adequate privacy for the dying patient and his/her family
8	Prepare the patient and/or family for the dying process	Provide information to the patient and/or family regarding the dying process
* ‘ICU Palliative Care Quality Assessment Tool’		

The respondents recommended that one item, namely item 43 ‘Minimize noxious stimuli (monitor noises, strong lights, etc.) after life-support is withdrawn’, should be removed.

In round 4, consensus (I-CVI 100%) was reached on all items (see Annexure B12).

Discussion: The respondents found 16 items simple, short, relevant and written in a language familiar to the target population (Tsang et al 2017:S80; Roberts, Holland, Prigerson, Sweeney et al 2017:60; Nadin, Miandad, Kelley et al 2017:10; Nemoto & Beglar 2013:3). One of the items was deleted as it was not relevant to measuring quality of EoLC in the ED (Roberts et al 2017:60). The rationale for recommending that the item on noise and strong lights be removed could be that healthcare professionals have little control in the ED over the environment as well as emphasising the medical-technical status of the patient rather than the noxious environment (McConnell, McCance & Melby 2016:39).

The fact that the respondents did not add any items in round 4 indicated that the selection of items was sufficient to measure the construct under study, namely quality of EoLC in the ED (Roberts et al 2017:60).

4.5 STAGE 2: EVALUATION BY TARGET POPULATION

In stage 2, the instrument was evaluated by the target population of experienced doctors and nurses with additional qualifications in emergency care, working in an ED in South Africa.

4.5.1 Respondents

A total of 33 respondents (14 doctors and 19 registered nurses) participated. Table 4.6 presents the respondents’ demographic information.

Table 4.6 Stage 2: Respondents' demographic information

Variable	Count (%)
Number of respondents	33 (100)
Gender	
Male	6 (18.2)
Female	27 (81.1)
Professional qualification	33 (100)
Doctor	14 (42)
Registered nurse	19 (58)
Sector	33 (100)
Public	
Doctors	6 (18.2)
Registered nurses	8 (24.2)
Private	8 (24.2)
Doctors	11 (33.3)
Registered nurses	

All the respondents (N=33) had an additional qualification in either emergency medicine (n=14) or emergency nursing (n=19). The respondents' experience in the ED ranged from 3 to 20 years (Mean = 10). Two respondents indicated that they had informal training in EoLC.

Discussion: The doctors (n=14) and the registered nurses (n=19) were from the private and the public sectors. The sample of 33 respondents was congruent with Beaton et al's (2000:3181) recommended 30 to 40 respondents. All the respondents had a formal postgraduate qualification in either emergency medicine (doctors) or emergency nursing (registered nurses).

4.5.2 Inputs on instructions, layout and Likert scale

The respondents were asked to give feedback on the instructions, layout and the 10-point Likert scale used in the instrument (see table 4.7).

Table 4.7 Stage 2: Summary of inputs on instructions, layout and Likert scale

Instructions	Layout	Likert scale
Relevance (CVI 100%)	Relevance (CVI 100%)	Two respondents suggested using a 5-point Likert scale

Discussion: The respondents agreed that the instructions and the layout were 100% relevant. Two respondents commented on the 10-point Likert scale and suggested using a 5-point scale. The researcher decided to keep the 10-point Likert scale because a 10-point scale gives more accurate measurements (see Section 4.4.1).

4.5.3 Inputs on items

The respondents reviewed the items on the instrument for relevance and clarity relating to the ED. All the items as adapted from Stage 1 were accepted and no rephrasing was suggested.

Discussion: The feedback obtained indicated that the respondents, a sample of the target population of doctors and registered nurses working in EDs in South Africa, found the instructions clear, the layout acceptable, and all the items relevant.

4.6 STAGE 3: EVALUATION BY EXPERTS

The aim of this stage was for the experts who developed the 'ICU Palliative Care Quality Assessment Tool' to evaluate the adapted instrument. However, none of the original authors of the instrument could participate. Consequently, the researcher used purposive sampling and asked one international and one national expert in EoLC in the ED to participate, namely a doctor (national) and a registered nurse (international). Both volunteered to participate.

4.6.1 Respondents

Of the respondents, one (doctor; national) had 13 years' experience in the ED and and a postgraduate qualification in EoLC, and one (registered nurse; international) had 20 years' experience in the ED. Both were female. Both respondents were working in the academic setting and one had published extensively.

4.6.2 Inputs on instructions, layout and Likert scale

The respondents were asked to give feedback on the instructions, layout and the Likert scale and items in the adapted instrument, now referred to as 'End-of-Life Care Quality Assessment in the Emergency Department' instrument. Consensus was reached that the layout and Likert scale were relevant. Table 4.8 summarises the inputs in Stage 3.

Table 4.8 Stage 3: Summary of inputs on instructions, layout and Likert scale

Instructions	Layout	Likert scale
The word "perception" to be added to the instructions	Relevance (CVI 100%)	Relevance (CVI 100%)
End-of-life care to be defined		
Only emergency care practitioners working in the ED should also complete the instrument.		

The respondents pointed out that the survey was on respondents' perceptions of quality end-of-life care in the ED and therefore the word "perception" should be added to the instructions about the scoring of quality of end-of-life care.

Both respondents suggested that the concept "end-of-life care" needed clarification since the focus of the entire instrument was on quality end-of-life care in the ED. One of the respondents referred to Razmaria's (2016:115) definition of end-of-life care.

The respondents also suggested that emergency care practitioners be added to the healthcare professionals who should participate in completing the survey as they worked in the ED, specifically in the private sector.

Discussion: Perceptions are important. Studies have been conducted on nurses' and family members' perceptions of quality of end-of-life care (Makaroun, Teno, Freedman, Kasper et al 2018:1730; Alquwez, Cruz, Almoghairi et al 2018:422). The *Oxford Advanced Learner's Dictionary* (2010:1087) defines *perception* as "the way you notice things, especially with the senses: our perception of reality; the ability to understand the true nature of something; an idea, belief or an image you have as a result of how you see or understand something". In this study, it was important to measure and maintain quality EoLC that meets what people think and feel about the service, therefore the respondents' suggestion was regarded as relevant**.**

The respondents suggested inserting Razmaria's (2016:115) definition: "End-of-life care in the ED refers to the care that healthcare professionals deliver to patients and their families at the end of the patient's life when death is imminent and normal life-saving treatments are futile." The definition was inserted. In the South African context, specifically in the private sector, emergency care practitioners work in the ED (MacFarlane, van Loggerenberg & Kloeck 2005).

4.6.3 Inputs on items

The respondents reviewed the items in the instrument for relevance and clarity for the ED setting. Table 4.9 summarises the feedback indicating which items required rephrasing. The suggestions of the national expert, familiar with the context, were accepted. (see Annexure D4).

Table 4.9 Stage 3: Summary of items which respondents suggested rephrasing

Sections	Items rephrased
A Demographic information	Emergency care practitioners added
B Communication within team, patient, families	1, 2, 4, 6, 7, 8
C Patient- and family-centred decision making	9, 10, 11, 12, 15, 16, 17, 18, 19, 20, 22, 23
D Continuity of care	24, 25, 26, 28
E Emotional and practical support	30, 31, 33, 36
F Symptom management and comfort care	39, 42
G Spiritual support for patients and families	44, 46
H Emotional and organisational support of the healthcare team	48, 49, 50, 51, 52, 53
I Overall assessment of the quality of end-of-life care by doctors and nurses and emergency care practitioners	58, 60, 62, 63, 64

The researcher rephrased the items according to the suggestions. All the suggestions for rephrasing the items were made by the South Africa expert. The international expert accepted the instrument as is. For example, item 24 in the original instrument (Annexure B) stated, “Forgo life-sustaining treatments in a way that ensures the patient’s and family’s preferences are respected.” The national respondent stated that the term “forgo” was not familiar in the South African setting and suggested that the word be replaced with “withhold”, which was done (see Annexure D4, item 24).

Table 4.10 lists two additional examples of rephrased items.

Table 4.10 Stage 3: Examples of rephrased items

Item	Original	Rephrased
2	Attending doctors meet at least once with the patient’s family	Doctors responsible for patient’s care meet at least once with the patient’s family.
8	Prepare the patient and/or family for the dying process	Provide information for the patient and/or family on the dying process

Discussion: The experts in EoLC nationally (emergency medicine specialist) and internationally (registered nurse) reviewed the drafted ‘Quality End-of-Life Care in the Emergency Department’ instrument. The experts reviewed the items and the South African expert rephrased 41 items. The expert from the South African context suggested rephrasing all the items, which may be due to her working in the ED in South Africa as well as having a postgraduate degree in palliative care. The expert respondents reviewed and evaluated the adapted ‘Quality End-of-Life Care in the Emergency Department’ instrument. The expert respondents’ main recommendations were adding the word “perception” to the instructions on assessing quality of end-of-life care and Razmaria’s (2016:115) definition of end-of-life care, and including emergency care practitioners as healthcare professionals who should participate in completing the survey as they worked in the ED, specifically in the private sector. In addition, 41 items were rephrased and the instrument was considered ready for validation in the pilot study in stage 4.

Objective 2: Validation of adapted instrument

4.7 STAGE 4 - PILOT STUDY

In Stage 4, a pilot study was done to validate the instrument which will be named ‘Perceptions of Quality End-of-Life Care in the Emergency Department’ (P-QEoLCED) instrument. See Annexure F.

4.7.1 Respondents

The researcher selected 315 respondents for the pilot study. The respondents consisted of doctors (n=55), registered nurses (n=246), and emergency care practitioners (n=14) working in both the private and public sectors in EDs in South Africa. Emergency care practitioners only participated in this stage following recommendations from the respondents in Stage 3. Table 4.11 presents the demographic profile of the respondents in the pilot study.

Table 4.11 Stage 4: Pilot study respondents' demographic information

Variable	Count (%)
Number of respondents	315 (N=100%)
Gender	
Male	60 (19)
Female	255 (81)
Professional qualification	315 (100)
Doctors	55 (17.5)
Degree	28 (50.9)
Master's	25 (45.5)
PhD	02 (3.6)
Registered nurses	246 (78.1)
Diploma	150 (61)
Degree	77 (31.3)
Master's	15 (6.1)
PhD	04 (1.6)
Emergency care practitioners	14 (4)
Advanced life support	12 (85.7)
Intermediate life support	Nil
Basic life support	02 (14.3)
Additional post-graduate qualification	123 (39)
Doctors	11 (20)
Emergency medicine	04 (36.4)
DiPPEC	04 (36.4)
Variable	**Count (%)**
FCEM	02 (18.2)
NERS	01 (9.1)
Registered nurses	105 (85.4)
Trauma nursing	80 (76.2)
ICU	11 (10.5)
Nursing administration	14 (13.3)
Occupational Health	05 (4.8)
Emergency care practitioners	2 (14.3)
Degree	01 (50)
Masters	01 (50)

Healthcare setting	315 (100)
Public	196 (62.2)
Doctors	37 (18.9)
Nurses	159 (81.1)
Emergency care practitioners	Nil (0)
Private	119(37.8)
Doctors	18 (15.1)
Nurses	87 (73.1)
Emergency care practitioners	14 (11.8)

The respondents' years of experience in the emergency environment ranged from 2 to 29 ±6 years (Mean = 9). None of the respondents reported that they had training in EoLC in the ED. The respondents reflected the number of healthcare professionals working in the ED, where the majority were registered nurses (78%; n=246) and emergency care practitioners (11.8%; n=14) worked predominantly in the pre-hospital environment and overtime within the ED in the private sector.

Discussion: A total of 315 respondents completed the questionnaire in Stage 4. The number of respondents was congruent with recommendations of between 300 and 1,000 respondents (Borsa et al 2012:423; Tsang et al 2017:S86).

4.7.2 Internal consistency of the instrument

Sections B to H of the instrument presented Clarke et al's (2003) seven domains, which were adapted for the ED. By completing the instrument, the respondents (doctors, registered nurses and emergency care practitioners) indicated their perceptions of the quality of EoLC provided in the ED by the healthcare team. In these sections the internal consistency of each domain and sub-domains was determined. Table 4.12 provides the Cronbach's alpha values. These values were only calculated for the doctors and registered nurses as the number of emergency care practitioners was too low (n=14) to fulfil the pre-requisites to calculate the Cronbach's alpha.

Table 4.12 Cronbach’s alpha as estimate of internal consistency of the different domains

Domain	Total sample	Doctors	Registered nurses
Communication			
Q1 to 4	0.82	0.79	0.83
Q5 to 8	0.85	0.80	0.85
All (Q1 to 8)	0.88	0.85	0.89
Family- and patient-centred care			
Q9 to 13	0.90	0.86	0.90
Q14 to 16	0.86	0.82	0.86
Q17 to 18	0.83	0.83	0.83
Q19 to 22	0.88	0.87	0.84
All (Q9 to 22)	0.95	0.95	0.96
Continuity of care			
Q23 to 24	0.55	0.77	0.44
Q2*5	Not applicable	Not applicable	Not applicable
Q26 to 27	0.80	0.87	0.78
All (23-27)	0.85	0.91	0.82
Emotional and practical support			
Q28 to 33	0.89	0.90	0.87
Q34 to 37	0.87	0.91	0.86
All (Q27-37)	0.93	0.94	0.92
Domain	**Total sample**	**Doctors**	**Registered nurses**
Symptom management and comfort care			
Q38 to 42	0.89	0.88	0.88
Spiritual support			
Q43	N/A	N/A	N/A
Q44 to 45	0.86	0.82	0.86
All (Q43 to 45)	0.86	0.82	0.86
Emotional and organisational support of the healthcare team			
Q46 to 51	0.96	0.97	0.95

**Cronbach’s alpha cannot be calculated for single questions (Question 25)*

The internal consistency of all the domains was above 0.8, indicating a good level of internal consistency (Moon 2017:53). Three of the Cronbach's alpha values for domains were above 0.9, which is considered excellent consistency.

Table 4.13 Two questions with low internal consistency

Question 23 and 24: Indicate how often do doctors in your ED...

	Never										**Always**
23. Inform the patient and/or the family regarding a doctor shift change?	0	1	2	3	4	5	6	7	8	9	10
24. Consider caring for the patient in the ED when death is likely to occur in the next 24 to 48 hours?	0	1	2	3	4	5	6	7	8	9	10

Source*: Perceptions of quality EoLC in the ED* (see Annexure F)

In the domain 'Continuity of care', in questions 23 and 24 (see Annexure F) the Cronbach Alpha for the registered nurses were below 0.7, indicating a low level of consistency, whereas the internal agreement for the consistency of doctors was good (Cronbach's Alpha > 0.7). See Table 4.13 for the two questions with low internal consistency. This means that there was less agreement between the registered nurses about the perceived quality of end-of-life care measured by these questions compared to the doctors.

Discussion: Except for two questions in the domain 'Continuity of care', all the sub-domains and domains had good to excellent internal consistency. The Cronbach's alpha values were similar to Nakazawa, Miyashita, Morita et al's (2009:764) level of internal consistency (0.88) in their study on the psychometric properties of an instrument to measure levels of knowledge about palliative care. The instrument 'Perceptions of Quality End-of-Life Care in the Emergency Department' is therefore valid in measuring the different domains in healthcare professionals' perceptions of the delivery of quality EoLC by the healthcare team in the ED.

4.7.3 Relationship between the doctors' and registered nurses' perceptions

Section I measured the respondent healthcare professionals' (doctors and registered nurses) perceptions of other healthcare professionals' (doctors, registered nurses and emergency care practitioners) quality of end-of-life care provided in the ED (see Table 4.14).

Table 4.14: Comparison of doctors and nurses, by item, with respect to the distribution over item categories

Domain	Doctor Frequency (%)	Registered nurse Frequency (%)	p-value
Communication			
Q52: Poor	5 (09)	45 (18)	0.136
Moderate	33 (62)	118 (48)	
Excellent	15 (28)	84 (34)	
Q53: Poor	5 (09)	36 (15)	0.295
Moderate	32 (60)	119 (48)	
Excellent	16 (30)	92 (37)	
Family- and patient-centred care			
Q54 Poor	6 (12)	35 (14)	0.272
Moderate	30 (58)	111 (45)	
Excellent	16 (31)	101 (41)	
Continuity of care			
Domain	**Doctor Frequency (%)**	**Registered nurse Frequency (%)**	**p-value**
Q55 Poor	5 (9)	54 (22)	0.090
Moderate	28 (52)	111 (45)	
Excellent	114 (46)	82 (33)	
Q56 Poor	6 (12)	30 (12)	1.000
Moderate	22 (42)	103 (42)	
Excellent	24 (46)	114 (46)	
Emotional and practical support			
57 Poor	5 (9)	6 (12)	0.044*
Moderate	21 (40)	22 (42)	

Excellent	27 (51)	24 (46)	
Symptom management and comfort care			
58 Poor	3 (6)	30 (12)	0.025*
Moderate	14 (27)	102 (41)	
Excellent	35 (67)	115 (47)	
Spiritual support			
59 Poor	7 (13)	62 (25)	0.108
Moderate	25 (45)	105 (43)	
Excellent	23 (42)	80 (32)	
Emotional and organisational support of the healthcare team			
60 Poor	11 (20)	93 (38)	0.043*
Moderate	26 (48)	87 (35)	
Excellent	17 (31)	67 (27)	
61 Poor	17 (30)	99 (40)	0.3740
Moderate	16 (29)	90 (36)	
Excellent		58 (23)	
62 Poor	8 (15)	43 (17)	0.920
Moderate	28 (52)	119 (48)	
Excellent	18 (33)	85 (34)	

**Significant at an Alpha level of 0.05*

In the three domains Emotional and practical support, Symptom management and comfort care, and Emotional and organisational support of the healthcare team (questions 57, 58 and 60), the doctors and the registered nurses differed significantly in their perceptions of the quality of EoLC delivered by the other healthcare team members in the ED.

Discussion: The instrument can differentiate between different healthcare professionals' perceptions of other team members' quality of EoLC care delivered. It is important to obtain objective feedback from other healthcare professionals' perceptions about the quality of care we deliver because it provides awareness that our perceived actions are different from others' views of what we do. As individuals, we are often unable to critically reflect and be aware of our own practice (McCormack et al 2010:98; Halpern 2009:12).

4.7.4 Feedback on the instrument

At the end of the 'Perceptions of quality End-of-Life Care in the Emergency Department' (P-QEoLCED) instrument, an open-ended question asked: Please add any additional feedback in the space below which you think would be useful for us to consider about the content and/or the format of this survey. The respondents were particularly positive about the structure, relevance and comprehensiveness of the instrument. Several respondents indicated that completion of the instrument led to an increase in knowledge about EoLC in the ED.

In addition, some respondents indicated that the instrument was 'too long' and also recommended that the perceptions of patients and families should be considered (see Annexure **F** for a summary of the feedback).

4.8 SUMMARY

This chapter systematically discussed the results of the adaptation and validation of the Perceptions of Quality End-of-life Care in Emergency Department (P-QEoLCED) instrument in the four stages. The instrument was evaluated, revised and reviewed in three stages and validated by 315 respondents in stage 4. The findings indicated that the instrument is suitable for use in EDs.

Chapter 5 presents the conclusions, strengths and limitations of the study and makes recommendations for practice and further research.

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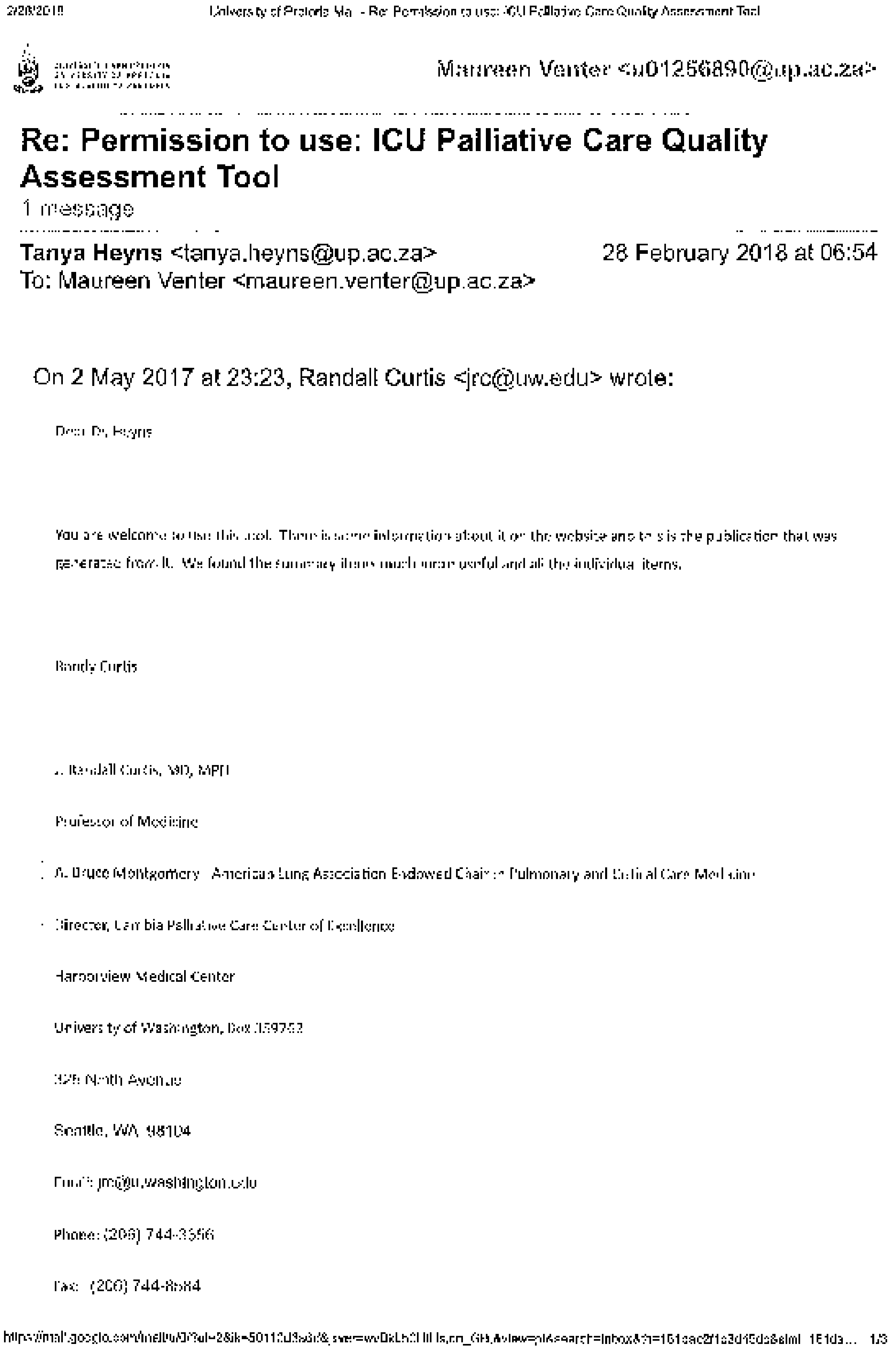
ANNEXURE A1

Permission to use original instrument: ICU palliative Care Quality Assessment Tool



2/28/2018 University of Pretoria Mail - Re: Permission to use: ICU Palliative Care Quality Assessment Tool

Maureen Venter <u01256890@up.ac.za>

Re: Permission to use: ICU Palliative Care Quality Assessment Tool

1 message

Tanya Heyns <tanya.heyns@up.ac.za> 28 February 2018 at 06:54
To: Maureen Venter <maureen.venter@up.ac.za>

On 2 May 2017 at 23:23, Randall Curtis <jrc@uw.edu> wrote:

Dear Dr Heyns

You are welcome to use this tool. There is some information about it on the website and this is the publication that was generated from it. We found the summary items much more useful and all the individual items.

Randy Curtis

J. Randall Curtis, MD, MPH

Professor of Medicine

A. Bruce Montgomery - American Lung Association Endowed Chair in Pulmonary and Critical Care Medicine

Director, Cambia Palliative Care Center of Excellence

Harborview Medical Center

University of Washington, Box 359762

325 Ninth Avenue

Seattle, WA 98104

Email: jrc@u.washington.edu

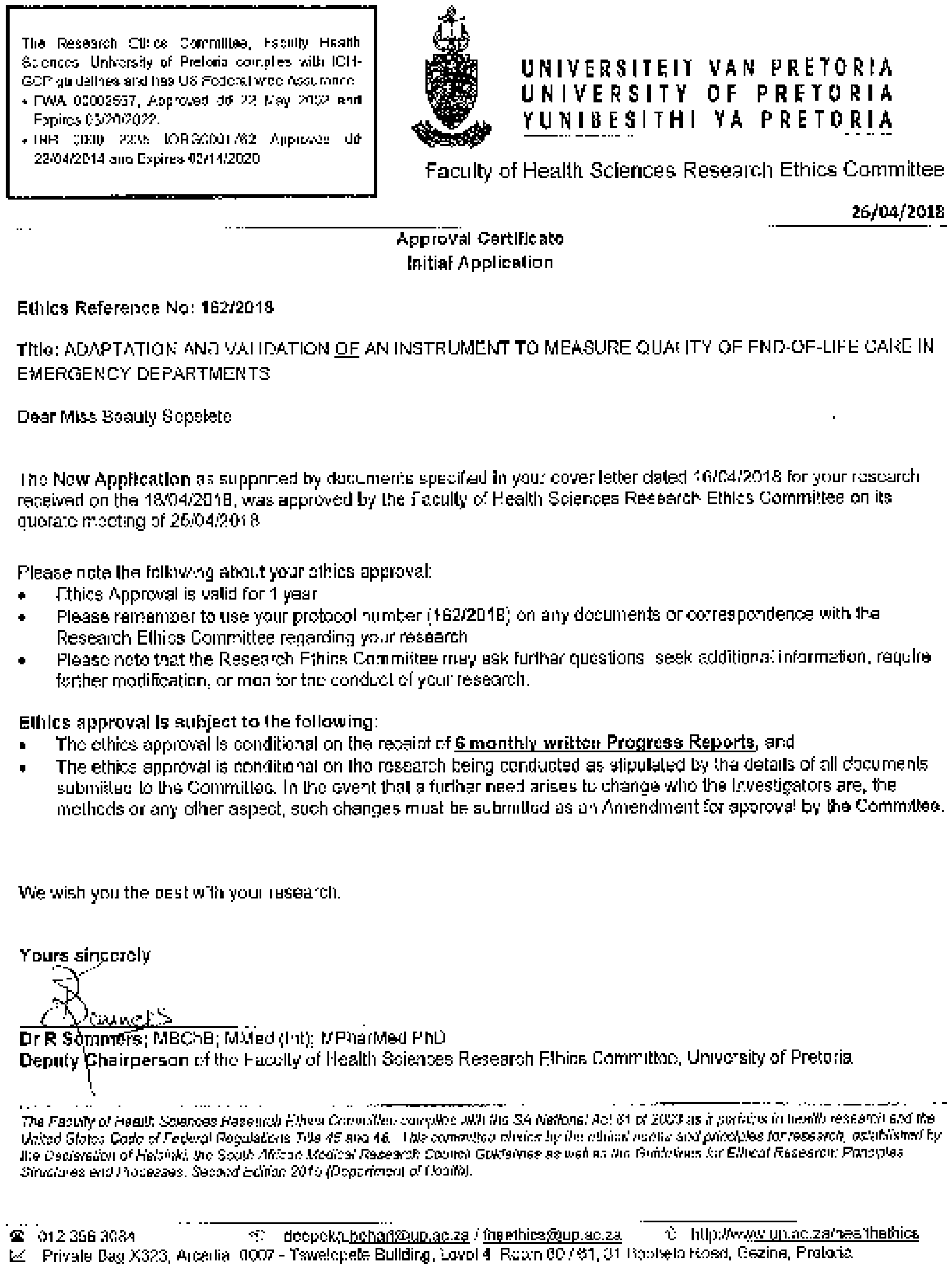
Phone: (206) 744-3356

Fax: (206) 744-8584

https://mail.google.com/mail/u/0/?ui=2&ik=50112d9a3d&jsver=wDkLh0lIlls.en_GB.&view=pt&search=inbox&th=161cac2f1a3d45da&siml=161da... 1/3

ANNEXURE A2

Ethics Approval: University of Pretoria



The Research Ethics Committee, Faculty Health Sciences University of Pretoria complies with ICH-GCP guidelines and has US Federalwide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

26/04/2018

Approval Certificate
Initial Application

Ethics Reference No: 162/2018

Title: ADAPTATION AND VALIDATION OF AN INSTRUMENT TO MEASURE QUALITY OF END-OF-LIFE CARE IN EMERGENCY DEPARTMENTS

Dear Miss Beauty Sepelete

The **New Application** as supported by documents specified in your cover letter dated 16/04/2018 for your research received on the 18/04/2018, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 25/04/2018

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (162/2018) on any documents or correspondence with the Research Ethics Committee regarding your research
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharMed PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 | deepeka.behari@up.ac.za / fhsethics@up.ac.za | http://www.up.ac.za/healthethics
Private Bag X323, Arcadia 0007 - Tswelopele Building, Level 4 Room 60 / 61, 31 Bophelo Road, Gezina, Pretoria

ANNEXURE B3

Original instrument: Measuring the quality of palliative care in the ICU

ICU Palliative Care Quality Assessment Tool
Attending/Housestaff Survey

Measuring the Quality of Palliative Care in the Intensive Care Unit

Mitchell Levy MD, J. Randall Curtis MD, MPH, John Luce MD,
Judith Nelson JD, MD

Ellen B. Clarke RN, MS, Ed.D. – Project Director

Institution ______________________________________

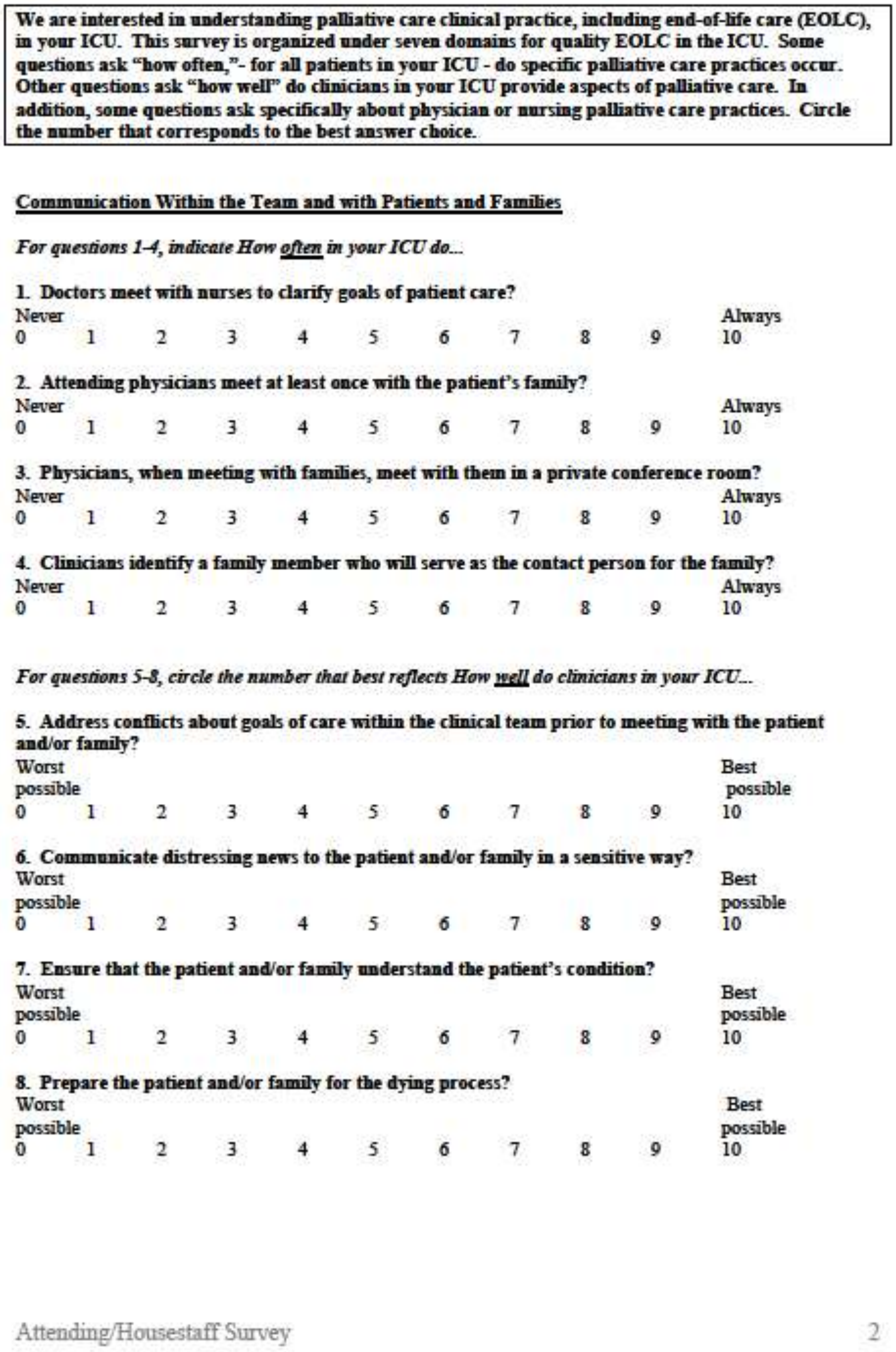
Type of Unit ______________________________________

Please check one of the following:

Housestaff ____

Attending ____

Date _____/_______/______
Month *Day* *Year*



We are interested in understanding palliative care clinical practice, including end-of-life care (EOLC), in your ICU. This survey is organized under seven domains for quality EOLC in the ICU. Some questions ask "how often,"- for all patients in your ICU - do specific palliative care practices occur. Other questions ask "how well" do clinicians in your ICU provide aspects of palliative care. In addition, some questions ask specifically about physician or nursing palliative care practices. Circle the number that corresponds to the best answer choice.

Communication Within the Team and with Patients and Families

For questions 1-4, indicate How often in your ICU do...

1. Doctors meet with nurses to clarify goals of patient care?

Never										Always
0	1	2	3	4	5	6	7	8	9	10

2. Attending physicians meet at least once with the patient's family?

Never										Always
0	1	2	3	4	5	6	7	8	9	10

3. Physicians, when meeting with families, meet with them in a private conference room?

Never										Always
0	1	2	3	4	5	6	7	8	9	10

4. Clinicians identify a family member who will serve as the contact person for the family?

Never										Always
0	1	2	3	4	5	6	7	8	9	10

For questions 5-8, circle the number that best reflects How well do clinicians in your ICU...

5. Address conflicts about goals of care within the clinical team prior to meeting with the patient and/or family?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

6. Communicate distressing news to the patient and/or family in a sensitive way?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

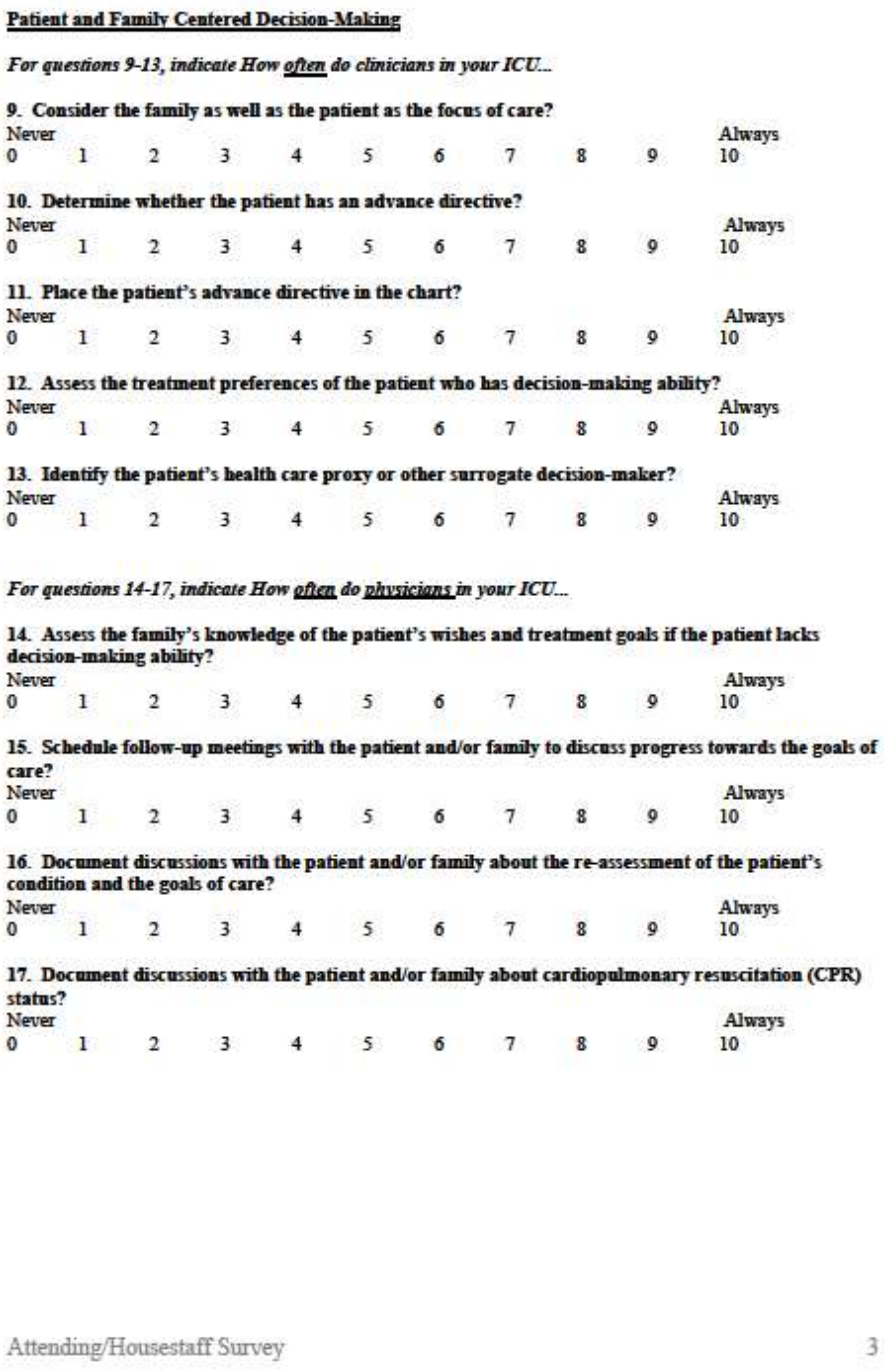
7. Ensure that the patient and/or family understand the patient's condition?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

8. Prepare the patient and/or family for the dying process?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Attending/Housestaff Survey 2



Patient and Family Centered Decision-Making

For questions 9-13, indicate How often do clinicians in your ICU...

9. Consider the family as well as the patient as the focus of care?
Never Always
0 1 2 3 4 5 6 7 8 9 10

10. Determine whether the patient has an advance directive?
Never Always
0 1 2 3 4 5 6 7 8 9 10

11. Place the patient's advance directive in the chart?
Never Always
0 1 2 3 4 5 6 7 8 9 10

12. Assess the treatment preferences of the patient who has decision-making ability?
Never Always
0 1 2 3 4 5 6 7 8 9 10

13. Identify the patient's health care proxy or other surrogate decision-maker?
Never Always
0 1 2 3 4 5 6 7 8 9 10

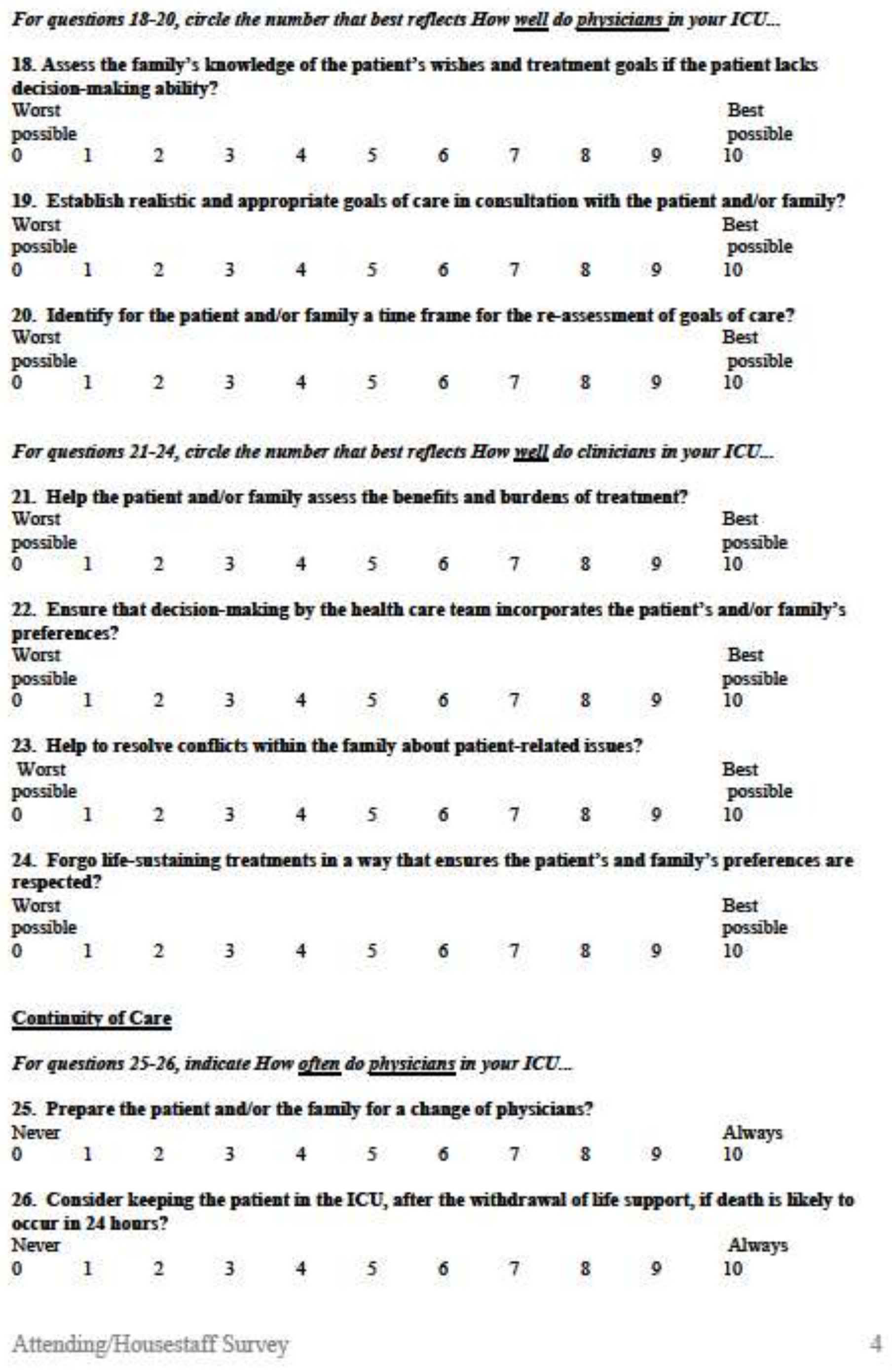
For questions 14-17, indicate How often do physicians in your ICU...

14. Assess the family's knowledge of the patient's wishes and treatment goals if the patient lacks decision-making ability?
Never Always
0 1 2 3 4 5 6 7 8 9 10

15. Schedule follow-up meetings with the patient and/or family to discuss progress towards the goals of care?
Never Always
0 1 2 3 4 5 6 7 8 9 10

16. Document discussions with the patient and/or family about the re-assessment of the patient's condition and the goals of care?
Never Always
0 1 2 3 4 5 6 7 8 9 10

17. Document discussions with the patient and/or family about cardiopulmonary resuscitation (CPR) status?
Never Always
0 1 2 3 4 5 6 7 8 9 10



For questions 18-20, circle the number that best reflects How well do physicians in your ICU...

18. Assess the family's knowledge of the patient's wishes and treatment goals if the patient lacks decision-making ability?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

19. Establish realistic and appropriate goals of care in consultation with the patient and/or family?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

20. Identify for the patient and/or family a time frame for the re-assessment of goals of care?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

For questions 21-24, circle the number that best reflects How well do clinicians in your ICU...

21. Help the patient and/or family assess the benefits and burdens of treatment?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

22. Ensure that decision-making by the health care team incorporates the patient's and/or family's preferences?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

23. Help to resolve conflicts within the family about patient-related issues?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

24. Forgo life-sustaining treatments in a way that ensures the patient's and family's preferences are respected?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Continuity of Care

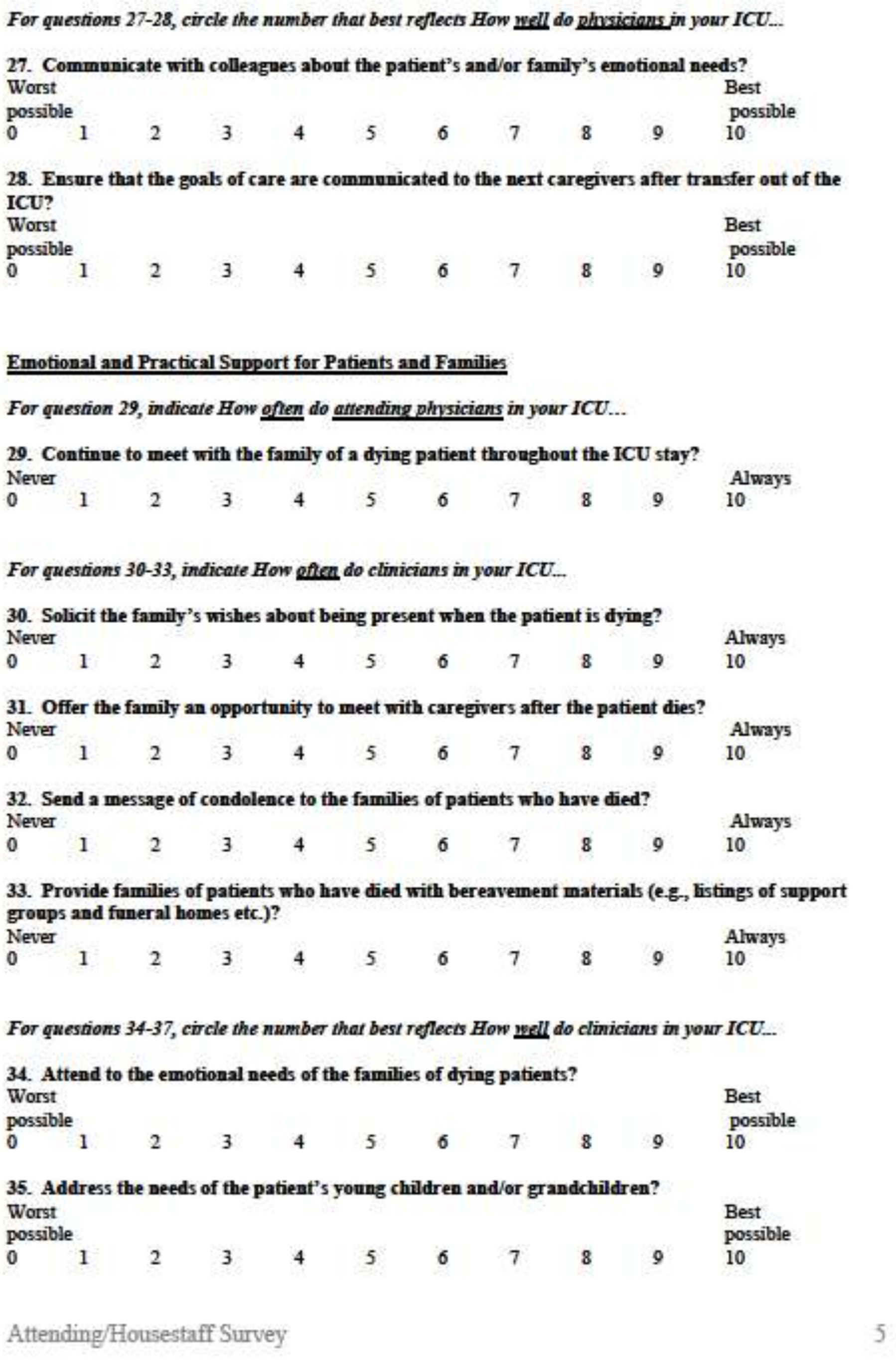
For questions 25-26, indicate How often do physicians in your ICU...

25. Prepare the patient and/or the family for a change of physicians?

Never										Always
0	1	2	3	4	5	6	7	8	9	10

26. Consider keeping the patient in the ICU, after the withdrawal of life support, if death is likely to occur in 24 hours?

Never										Always
0	1	2	3	4	5	6	7	8	9	10



For questions 27-28, circle the number that best reflects How well do physicians in your ICU...

27. Communicate with colleagues about the patient's and/or family's emotional needs?

Worst possible 0 1 2 3 4 5 6 7 8 9 10 Best possible

28. Ensure that the goals of care are communicated to the next caregivers after transfer out of the ICU?

Worst possible 0 1 2 3 4 5 6 7 8 9 10 Best possible

Emotional and Practical Support for Patients and Families

For question 29, indicate How often do attending physicians in your ICU…

29. Continue to meet with the family of a dying patient throughout the ICU stay?

Never 0 1 2 3 4 5 6 7 8 9 10 Always

For questions 30-33, indicate How often do clinicians in your ICU...

30. Solicit the family's wishes about being present when the patient is dying?

Never 0 1 2 3 4 5 6 7 8 9 10 Always

31. Offer the family an opportunity to meet with caregivers after the patient dies?

Never 0 1 2 3 4 5 6 7 8 9 10 Always

32. Send a message of condolence to the families of patients who have died?

Never 0 1 2 3 4 5 6 7 8 9 10 Always

33. Provide families of patients who have died with bereavement materials (e.g., listings of support groups and funeral homes etc.)?

Never 0 1 2 3 4 5 6 7 8 9 10 Always

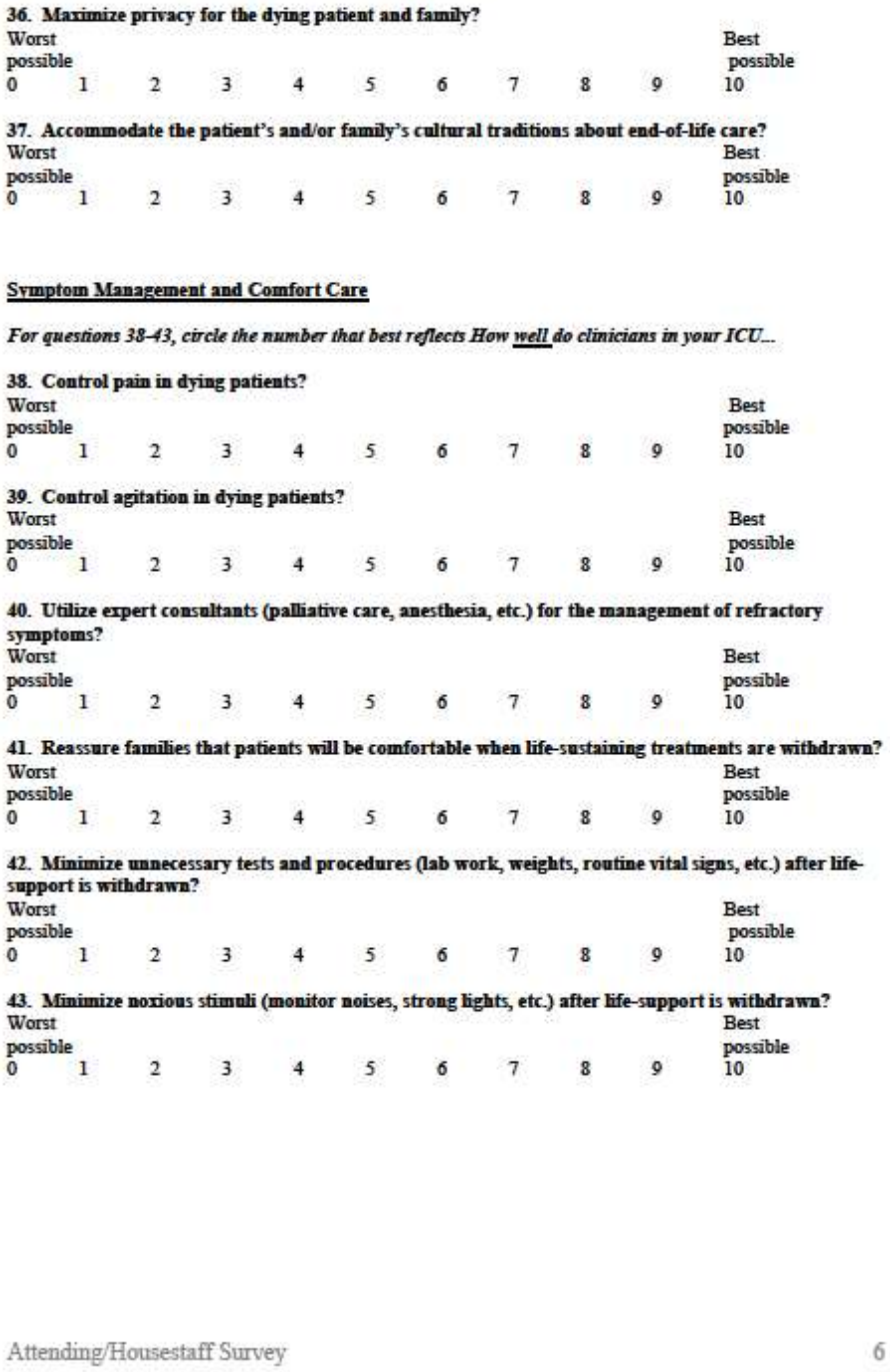
For questions 34-37, circle the number that best reflects How well do clinicians in your ICU...

34. Attend to the emotional needs of the families of dying patients?

Worst possible 0 1 2 3 4 5 6 7 8 9 10 Best possible

35. Address the needs of the patient's young children and/or grandchildren?

Worst possible 0 1 2 3 4 5 6 7 8 9 10 Best possible



36. Maximize privacy for the dying patient and family?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

37. Accommodate the patient's and/or family's cultural traditions about end-of-life care?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Symptom Management and Comfort Care

For questions 38-43, circle the number that best reflects How well do clinicians in your ICU...

38. Control pain in dying patients?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

39. Control agitation in dying patients?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

40. Utilize expert consultants (palliative care, anesthesia, etc.) for the management of refractory symptoms?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

41. Reassure families that patients will be comfortable when life-sustaining treatments are withdrawn?

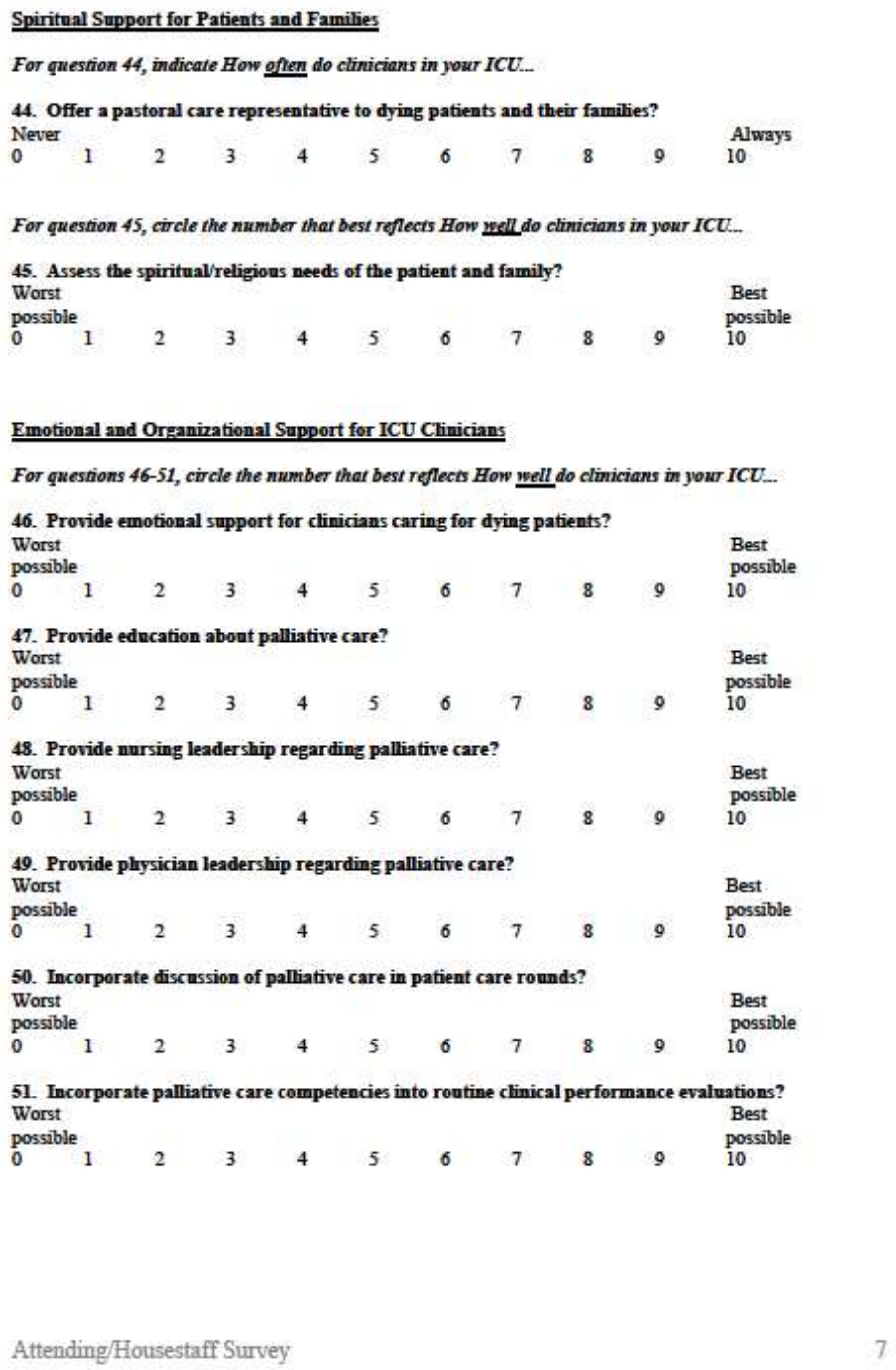
Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

42. Minimize unnecessary tests and procedures (lab work, weights, routine vital signs, etc.) after life-support is withdrawn?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

43. Minimize noxious stimuli (monitor noises, strong lights, etc.) after life-support is withdrawn?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10



Spiritual Support for Patients and Families

For question 44, indicate How often do clinicians in your ICU...

44. Offer a pastoral care representative to dying patients and their families?

Never										Always
0	1	2	3	4	5	6	7	8	9	10

For question 45, circle the number that best reflects How well do clinicians in your ICU...

45. Assess the spiritual/religious needs of the patient and family?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Emotional and Organizational Support for ICU Clinicians

For questions 46-51, circle the number that best reflects How well do clinicians in your ICU...

46. Provide emotional support for clinicians caring for dying patients?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

47. Provide education about palliative care?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

48. Provide nursing leadership regarding palliative care?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

49. Provide physician leadership regarding palliative care?

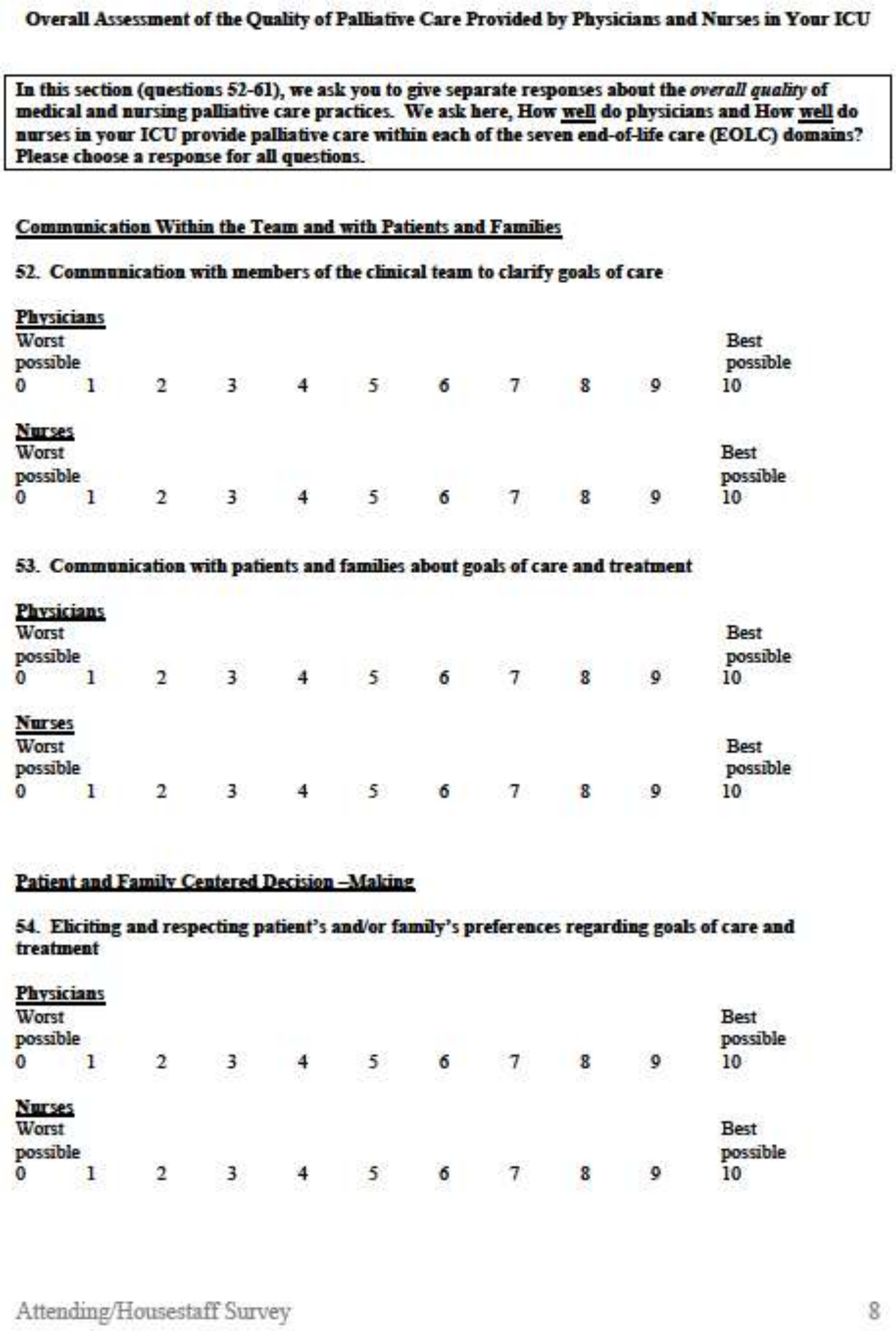
Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

50. Incorporate discussion of palliative care in patient care rounds?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

51. Incorporate palliative care competencies into routine clinical performance evaluations?

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10



Overall Assessment of the Quality of Palliative Care Provided by Physicians and Nurses in Your ICU

In this section (questions 52-61), we ask you to give separate responses about the *overall quality* of medical and nursing palliative care practices. We ask here, How well do physicians and How well do nurses in your ICU provide palliative care within each of the seven end-of-life care (EOLC) domains? Please choose a response for all questions.

Communication Within the Team and with Patients and Families

52. Communication with members of the clinical team to clarify goals of care

Physicians

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Nurses

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

53. Communication with patients and families about goals of care and treatment

Physicians

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Nurses

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Patient and Family Centered Decision –Making

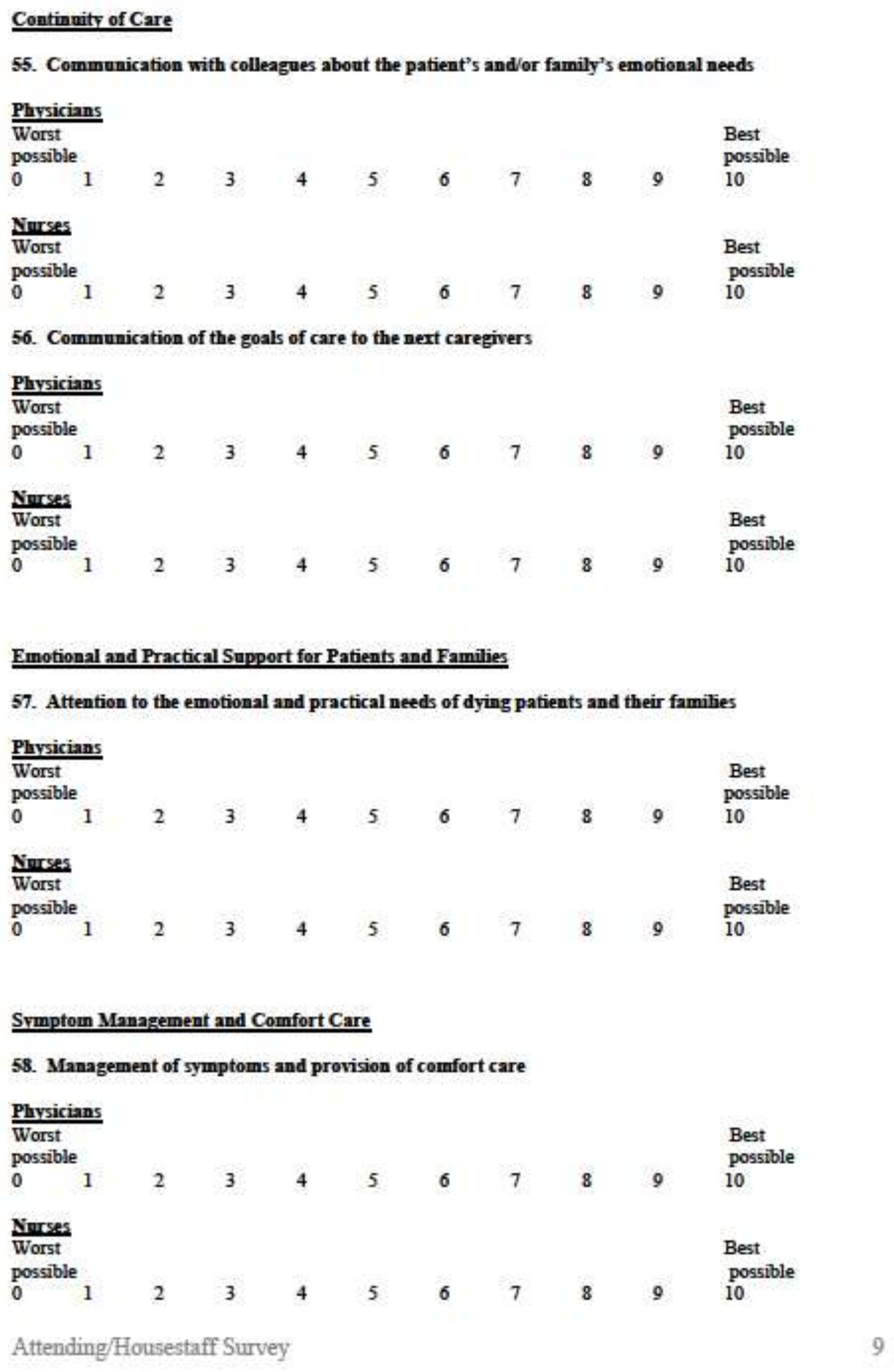
54. Eliciting and respecting patient's and/or family's preferences regarding goals of care and treatment

Physicians

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Nurses

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10



Continuity of Care

55. Communication with colleagues about the patient's and/or family's emotional needs

Physicians
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Nurses
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

56. Communication of the goals of care to the next caregivers

Physicians
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Nurses
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Emotional and Practical Support for Patients and Families

57. Attention to the emotional and practical needs of dying patients and their families

Physicians
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Nurses
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Symptom Management and Comfort Care

58. Management of symptoms and provision of comfort care

Physicians
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Nurses
Worst possible
0 1 2 3 4 5 6 7 8 9 10
Best possible

Attending/Housestaff Survey 9

Spiritual Support for Patients and Families

59. Assessment of the spiritual/religious needs of the patient and family

Physicians

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Nurses

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Emotional and Organizational Support for ICU Clinicians

60. Provision of emotional support for clinicians caring for dying patients

Physicians

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Nurses

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

61. Provision of education about palliative care

Physicians

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Nurses

Worst possible										Best possible
0	1	2	3	4	5	6	7	8	9	10

Please add any additional comments in the space below which you think would be useful for us to consider about the content and/or the format of this survey.

Thank you for taking the time to complete this survey. We know that your time is important and that there are many demands on you. Your input is essential to on-going efforts to improve palliative care in the ICU.

ANNEXURE F

Perceptions of Quality end-of-life care in the emergency department (P-QEoLCED)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Perceptions of Quality End-of-Life Care in the Emergency Department
(P-QEoLCED)
Members of the Healthcare Team Survey

(Sepelete, Heyns and Mostert – *Adapted and validated from the work by Clarke, Levy, Curtis, Luce & Nelson, 2003)*

Instructions

We are interested in understanding your perceptions on the quality of end-of-life care (EOLC) provided in your emergency centre (ED). This survey is organised under the ***seven domains*** for quality EOLC. Some questions ask '*how often*' - for all patients in your ED – are EOLC initiated. Other questions ask '*how well'* do doctors, nurses and emergency care practitioners (members of the healthcare team) in your ED provide aspects of EOLC. In addition, some questions ask specifically about doctors or nurses' end-of-life care practices in your ED.

Please answer **ALL** the questions.

Indicate your option with a ***cross* (x)** and/or ***provide further information*** if required.

You are welcome to add comments at the end of the survey.

Abbreviation and term clarification

Term	*Abbreviation*	*Definition*
Doctor		*Medical doctor that is primarily involved in patient care in the emergency department*
End-of-life care	*EOLC*	*The care that members of healthcare team initiate and/provide to adult patients and their families in the ED at the end of patient's life when death is imminent and normal life saving treatment is futile*
Emergency care practitioner		*All emergency care practitioners (basic, intermediate and advanced) who work in the ED (permanent or shifts) and involved in patient care in the ED*

Emergency department	*ED*	*A unit in a public or private hospital in South Africa where members of the healthcare team deliver 24-hour care to patients with end-of-life care needs*
Family		*A person or persons who has a close, meaningful relationship with the patient with end-of-life needs, not necessarily blood related*
Members of the healthcare team		*Doctors, nurses and emergency care practitioners that are primarily involved in patient care in the ED*
Nurse		*All nurses (professional, enrolled and enrolled assistant) involved in the care of patients in the ED*

Section A: Demographic information

Please provide the following information, by indicating your option with a ***cross (x)*** and/or ***providing further information*** if required.

Sex	*Male*		*Female*			
Professional qualification	*Doctor*					
	Nurse					
*If you are a **nurse**, please indicate your qualification*	*Professional nurse*		*Enrolled nurse*			
	Enrolled assistant nurse					
	Emergency care practitioner					
*If you are an **emergency care practitioner**, please indicate level*	*Advanced*		*Intermediate*		*Basic*	
If other, please indicate						

Indicate your ***highest qualification*** *(degree, masters, PhD)*				
Do you have ***additional post-graduate qualification(s)***	*Yes*		*No*	
If ***yes****, please list your additional post-graduate qualifications*				
Years of experience *in ED*	____________________*years*			
In which ***healthcare setting*** *are you currently working?*	*Public*		*Private*	
Do you have experience ***in initiating or providing end-of-life care*** *in the emergency department?*	*Yes*		*No*	
If ***yes****, please explain your experience in end-of-life care briefly*				
Have you had any ***training in end-of-life care***	*Yes*		*No*	
If ***yes****, please explain the training you had in end-of-life care briefly*				

Section B: Communication within the team and with patients and families

Questions 1 to 4: Indicate how often in your ED do…

	Never										***Always***
1. Doctors discuss and clarify goals of patient care with nurses?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
2. Doctors responsible for the patient's care meet at least once with the patient's family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
3. Doctors, when discussing end-of-life care with families, meet with them in a private area?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

4. Members of healthcare team identify a family member who will serve as the contact person for the family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 5 to 8: Indicate how well do members of healthcare team in your ED…

	Worst possible										**Best possible**
5. Address conflict about goals of care within the healthcare team prior to meeting with the patient and/or family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
6. Communicate distressing news to the patient and/or family in a compassionate way?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
7. Ensure that the patient and/or family understand the patient's condition and prognosis?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
8. Provide information to the patient and/or family regarding the dying process?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section C: Patient and family centred decision-making

Questions 9 to 13: Indicate how often do members of healthcare team in your ED…

	Never										**Always**
9. Consider the patient's and/or family's wishes when deciding on the goals of care?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
10. Enquire about whether the patient has an advanced directive stating his/her wishes about end-of-life care?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
11. Document or file the patient's advanced directive to ensure easy access?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
12. Discuss patient's treatment options and preferences with patients?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
13. Identify the patient's family member with responsibility of making medical decisions?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 14 to 16: Indicate how often do members of the healthcare team in your ED…

	Never										**Always**
14. Assess the family's knowledge of the patient's wishes and treatment goals when the patient lacks decision-making ability?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
15. Document the discussions with the patient and/or family following the review of the patient?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
16. Document discussions with the patient and/or family about the effectiveness of cardiopulmonary resuscitation (CPR)?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 17 to 18: Indicate how well do doctors in your ED…

	Worst possible										**Best possible**
17. Establish realistic and appropriate goals of care in consultation with the patient and/or family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

18. In collaboration with the healthcare team and patient/family, identify a time frame for the re-assessment of goals of care?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 19 to 22: Indicate how well do members of healthcare team in your ED...

	Worst possible										***Best possible***
19. Assist the patient and/or family to weigh up the benefits and burdens of specific treatment options?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
20. Ensure that decision-making by the health care team incorporates the patient's and/or family's preferences?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
21. Help to resolve conflict between the patient and the family or between family members about patient-related issues?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
22. Respect the wishes of the patient and/or family when withholding or withdrawing life-sustaining treatment?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section D: Continuity of care

Questions 23 to 24: Indicate how often do doctors in your ED...

	Never										***Always***
23. Inform the patient and/or the family regarding a doctor shift change?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
24. Consider caring for the patient in the ED when death is likely to occur in the next 24 to 48 hours?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 25: Indicate how often do nurses in your ED...

	Never										***Always***
25. Inform the patient/family regarding a nursing shift change?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 26 to 27: Indicate how well do doctors in your ED...

	Worst possible										***Best possible***
26. Communicate with colleagues about the patient's and/or family's emotional needs?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
27 Ensure that the goals of care are communicated to the next members of the healthcare team after transfer out of the ED?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section E: Emotional and practical support for patients and families

Question 28 to 33: Indicate how often do attending healthcare team members s in your ED...

	Never										***Always***
28 Assess the emotional needs of the patient and family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
29 Continue to meet with the family of a dying patient throughout the ED stay?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
30 Inquire about the family's wishes regarding being present when the patient is dying?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

31 Offer the family an opportunity to meet with members of healthcare team after the patient dies?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
32 Send a message of condolence to the families of patients who have died?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
33 Provide families of patients who have died with information about grief and losses?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Questions 34 to 37: Indicate how well do members of healthcare team in your ED...

	Worst possible										**Best possible**
34 Attend to the emotional needs of the families of dying patients?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
35 Address the needs of the patient's young children and/or grandchildren?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
36 Ensure adequate privacy for the dying patient and his/her family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
37 Accommodate the patient's and/or family's cultural needs during end-of-life care?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section F: Symptom management and comfort care

Questions 38 to 42: Indicate how well do members of healthcare team in your ED...

	Worst possible										**Best possible**
38 Control pain in dying patients?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
39 Manage agitation in dying patients?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
40 Utilise expert consultants (palliative care, anaesthesia, etc.) for the management of refractory symptoms?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
41 Reassure family that patients will be comfortable when life-sustaining treatment are withdrawn?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
42 Minimise inappropriate tests and procedures (lab work, weight, routine vital signs, etc.) after the decision is made that comfort care is the focus of care?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section G: Spiritual support for patients and families

Question 43: indicate how often do members of healthcare team in your ED…

	Never										**Always**
43 Assess the spiritual/religious needs of the patient and family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Question 44 to 45: Indicate how well do members of healthcare team in your ED...

	Worst possible										**Best possible**
44 Provide spiritual/religious support to the dying patients and their families?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
45 Remain non-judgemental to the spiritual/religious/traditional practices of the patient/family?	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section H: Emotional and organisational support for members of healthcare team

Questions 46 to 51:- Indicate how well do members of healthcare team in your ED...

		Worst possible										***Best possible***
46	*Provide emotional support for those caring for dying patients?*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
47	*Provide continuous education to members of healthcare team about end-of-life care?*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
48	*Provide nursing leadership in support of end-of-life care?*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
49	*Provide doctor leadership in support of end-of-life care?*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
50	*Incorporate discussions of end-of-life care during handover?*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
51	*Incorporate end-of-life care competencies in continuous development programmes?*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Section I: Overall assessment of the quality of end-of-life care provided by Doctors, nurses and emergency care practitioners in your ED

In this section (questions 52-62), we ask you to give separate responses about your perceptions of the *overall quality* of doctors, nurses and emergency care practitioners end-of-life care practices in the ED.

We ask here, how well do **Doctors** and how well do **Nurses** in your emergency department initiate and/or provide end-of-life care? Please choose a response for all questions. Indicate your option with a ***cross (X)***, first relating to doctors and then relating to nurses.

Communicate with patient and families about goals of care and treatment

52 Communicate within the healthcare team involved in the current patient care to clarify goals of care

		Worst possible										***Best possible***
a)	*Doctors*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
b)	*Nurses*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
c)	*Emergency care practitioners*	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

53 Communicate with patient and family about goals of care and treatment goals

	Worst possible										Best possible
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Patient and family-centred decision-making

54 Elicit and respect patient's and/or family's preferences regarding goals of care and treatment options

	Worst possible										Best possible
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Continuity of care

55 Communicate with colleagues about the patient's and/or family's emotional needs

	Worst possible										Best possible
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

56 Communicate the goals of care to the next members of the healthcare team

	Worst possible										Best possible
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Emotional and practical support for patients and families

57 Give attention to emotional and practical needs of the dying patient and family

	Worst possible										Best possible
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Symptom management and comfort care

58 Manage the distressing symptoms and keep the patient comfortable

	Worst possible										Best possible
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Spiritual support for patients and families

59 Asses the spiritual/religious/cultural needs of the patient and family

	Worst possible										**Best possible**
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Emotional and organisational support for ED members of healthcare team

60 Provide emotional support for members of healthcare team caring for end-of-life patient

	Worst possible										**Best possible**
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

61 Provide education about end-of-life care to members of the healthcare team

	Worst possible										**Best possible**
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

62 How well do doctors/nurses consider the ethical principles when addressing ethical issues relating to end-of-life care?

	Worst possible										**Best possible**
a) Doctors	0	1	2	3	4	5	6	7	8	9	10
b) Nurses	0	1	2	3	4	5	6	7	8	9	10
c) Emergency care practitioners	0	1	2	3	4	5	6	7	8	9	10

Please add any additional feedback in the space below which you think would be useful for us to consider about the content and/or the format of this survey.

Thank you *for taking the time to complete the survey. We know that your time is important and that there are many demands on you. Your input is essential to on-going efforts to improve end-of-life care in the ED*