Patients' Experiences of Acute Deterioration and Medical Emergency Team (MET) Encounter: A Grounded Theory Study

Catherine Chung

Student ID: 30028134

RN, BN, GradCert.HPE, GradDip.Emerg, MAdvNursgPrac

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Federation University

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Table of Contents

Table of Tables

Abstract

Globally, considerable effort has been made to ensure hospital patients whose clinical condition deteriorates receive timely and appropriate care. Research suggests that hospitals have increasing numbers of patients who are more likely to become seriously ill during their admission due to complex problems. Recently, patient experience has been recognised as a means of assessing healthcare delivery with healthcare services across the world gathering patient experience or satisfaction data. Acute deterioration is unique and complex for all involved. However, little is known about this experience from the patient's perspective.

The purpose of this study was to generate theory about processes patients engage in when experiencing acute deterioration and MET encounter. Also, the research aimed to recognise and explain the factors that mediate patients' experiences. The findings of this study contribute to a growing body of knowledge that will improve patient care and practice guidelines for healthcare professionals.

Underpinned by the theoretical framework of symbolic interactionism, grounded theory was employed for this study. From it ontological, epistemological, and methodological underpinnings, constructivist grounded theory was considered the most suitable approach. Using purposive sampling, in-depth semi-structured interviews were conducted with 27 patients across three Australian healthcare services. Data were collected over a 12-month period, between May 2018 – May 2019 and analysed using constant comparative analysis.

The theoretical model '*Unravelling a complex experience: contextualising patients' experiences of acute clinical deterioration and Medical Emergency Team (MET) encounter*' emerged, offering a possible explanation of patients' actions and processes. Most patients began their journeys feeling something was wrong which triggered emotional changes (*experiencing changes-before the encounter*). Patient experience was influenced by a combination of physical and psychological changes and a MET response (*perceiving the reality - the encounter*). After the MET encounter, some patients searched for deeper understandings about their illnesses and the events that occurred, whereas others managed without further reflection (*reflecting on the event-after the encounter*).

Contextual conditions emerged influencing patients' experiences with three broad mediating factors identified. Some participants identified that their acute deterioration and subsequent MET encounter was unexpected, and they perceived the nature of their illness (before their acute deterioration) as stable, based on what they had been told by medical staff (*expectations and illness perception*). Many participants acknowledged that their experience was dependent on the health care

professionals who were caring for them at the time (*relationship with the MET*). Past experiences of illness and hospitalisation played an important role in participants' abilities to conceptualise their experiences of acute deterioration and MET encounter (*past experiences*). These factors exerted a significant influence on participants' experiences and helps to explain the differences between them.

Unravelling a complex experience: Conceptualising patients' experiences of acute deterioration and MET encounter offers a possible explanation of patients' meanings, actions and processes when experiencing acute deterioration and MET encounter. The theory leads to recommendations that healthcare organisations gather data about patients' experiences of acute deterioration and MET encounters, as these provide insights and opportunity to identify challenges that can be addressed.. Findings provide an explanatory framework for similar phenomena and increase awareness of patients' experiences to ultimately inform health policy and improve patient care. The findings highlight the need for healthcare services to instigate strategies that support patients who have experienced acute deterioration. Further research could evaluate the effectiveness of implemented strategies.

Thesis including published/accepted/submitted works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes one original paper published in a peer reviewed journal and two submitted for publication. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the nursing and midwifery under the supervision of Professor Simon Cooper and Professor Lisa McKenna.

In the case of *(Chapter 1 and Chapter 5*) my contribution to the work involved the following:

Table 1: Thesis including published/accepted/submitted works declaration

Thesis Chapter	Publication Title	Status	Nature and % of student contribution
2	Patients' experiences of acute deterioration: A scoping review	Published *International Journal of Nursing Studies*	80% concept development, key ideas, development and writing up
6	Unravelling a complex experience: Contextualising patients' experiences of acute deterioration and Medical Emergency Team (MET) encounter: A grounded theory study	Accepted subject to minor changes *Nursing Open*	80% concept development, key ideas, development and writing up
7	Contextual factors influencing patients' experiences of acute clinical deterioration and MET encounter: A grounded theory study	Under review *Journal of Advanced Nursing*	80% concept development, key ideas, development and writing up

I have / have not renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Student signature: Date: 27/03/21

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author, I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature: Date: 27/03/21

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Glossary of Terms

Medical Emergency Team (MET): also known as a rapid response team (RRT). A MET provides appropriate and timely emergency assistance or advice to manage the deterioration patient.

Members of the MET: are specially trained nurses and medical staff who have the necessary training, skills, and equipment to deliver urgent on-site treatment and management to the deteriorating patient.

MET Encounter: The Cambridge Dictionary (2020) refers to ‘encounter’ as meeting someone unexpectedly. In this thesis, *MET encounter* is referred to participants’ unexpected meeting with a MET.

Abbreviations

ACSQHC	Australian Commission on Safety and Quality in Health Care
CCU	Critical care unit
CGT	Constructivist grounded theory
ED	Emergency Department
GT	Grounded theory
GTM	Grounded theory methodology
ICU	Intensive care unit
MET	Medical emergency team
NHMRC	National Health and Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NSQHS	National Safety and Quality Health Service
RRT	Rapid response team
WHO	World Health Organisation

CHAPTER ONE

Setting the Scene

Chapter One: Setting the Scene

1.1 Introduction

> "It wasn't until a few days later in this room I heard that 'MET call' and thought what is that? And I looked it up [on the internet] and thought "Oh that happened to me!" (Guinane et al., 2018, p. 14).

This dissertation presents a qualitative study that explores patients' experiences of acute deterioration and medical emergency team (MET) encounter. A MET encounter describes a hospital patient's unexpected encounter with a MET due to experiencing acute deterioration. Grounded theory methodology (GTM) was utilised to explore the phenomenon and construct a relevant theory. Patients from a variety of clinical areas who experienced acute deterioration and MET encounter participated in the study.

Chapter one introduces the reader to the study and the thesis structure. Initially the impetus for the study and the position of the researcher is discussed. This is followed by an overview of the purpose and significance of the research. Following this is a summary of relevant background in order to contextualise the study. Finally, an outline of the thesis structure is presented to inform the reader to the organisation and scope of the dissertation.

1.2 Definitions

Acute Deterioration: According to the National Safety and Quality Health Service (NSQHS) Standards (2017), acute deterioration is defined as "physiological, psychological or cognitive changes that many indicate a worsening of the patient's health status; this may occur across hours or days" (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2017, p. 67). Throughout this thesis, 'acute deterioration' will be used to describe an experience where there is a change in a hospital patient's physiological, cognitive and mental state resulting in a MET encounter.

Patient Experience: Patient experience is a vital component of quality health care. Internationally, many countries are now gathering patient experience or satisfaction data as it is recognised as a way of assessing healthcare quality and delivery (Chung et al., 2020; Edwards et al., 2014). It is well documented that the benefits of improving a patient's experience include increased satisfaction, reduced length of stay, improved patient outcomes and reduction of costs (Chung et al., 2020; Edward et al., 2014; Epstein et al., 2010; Wolf et al., 2012). According to *Standard 2 – Partnering with Consumer Standard* of the 2017 NSQHS Standards, effective partnerships, high quality health care and improved patient safety is linked to positive patient experiences (ACSQHC, 2017).

Medical Emergency Team (MET) / Rapid Response Team (RRT): MET, also known as RRT, are widely used throughout hospitals in Australia and New Zealand (White et al., 2015). The MET/RRT systems were introduced to improve the recognition, response time and management of deteriorating ward patients by hospital clinicians, aiming to reduce cardiorespiratory arrest and mortality rates (Devita et al., 2006; Guinane et al., 2018). Current research indicates that MET systems now exist within two-thirds of all Australian hospitals and effect more than 14,700 patients each year (White et al., 2015). A key responsibility of health care services is to ensure systems are in place for clinicians to escalate care and call for emergency assistance for patients with severe clinical deterioration (Cooper et al, 2016). The requirement for hospitals to implement MET/RRT systems is specified in Standard 8 – *Recognising and Responding to Acute Deterioration* developed by ACQSHC (2017). MET has been described as "bringing critical care expertise to the bedside of clinically deteriorating patients residing in general hospital wards with the aim of preventing adverse outcomes, specifically death or cardiorespiratory arrest" (Garrubba & Joseph, 2019, p. 1). Throughout this thesis - 'MET' will be used to describe a rapid response system used to escalate care when a patient meets the following criteria:

- "Agreed vital sign parameters and other indicators of physiological deterioration
- Agreed indicators of deterioration in mental state
- Agreed parameters and other indicators for calling emergency assistance
- Patient pain or distress that is not able to be managed using available treatment
- Worry or concern in members of the workforce, patients, carers and families about acute deterioration." (ACQSHC, 2017, p. 146)

1.3 Impetus for the Study

While practising as a registered nurse and clinical educator within the acute care setting, I have provided care to many patients, across the life span, who have experienced physiological deterioration resulting in a MET review. One of those patients was a 43-year-old male who I will refer to as 'Tom'. Tom presented to the emergency department with a three-day history of shortness of breath. He had no flu-like symptoms and, aside from being obese, Tom had no other relevant past medical history. Tom was bought into the resuscitation bay for assessment until a less acute bed within the department became available. I cared for Tom and completed his assessment while waiting for a medical review and transfer out of the resuscitation bay. A short period of time passed and Tom's work of breathing increased, he became unsettled and voiced fear as he did not understand what was happening to him. During his medical review, Tom's condition deteriorated and his condition became unstable. Tom required Bilevel Positive Airway Pressure (BiPAP) and medication to support his breathing. After initial investigations, Tom was diagnosed with cardiomyopathy and was treated accordingly. Once Tom's condition was classified as stable, he was transferred to the cardiology ward for further management.

That same day, Tom required a MET review due to abnormal vital signs. I was on the response team and attended Tom's MET review. Due to the number of health care professionals in attendance I was not required to take a specific role and instead observed the event. Tom's work of breathing had increased, and he was unsettled. I observed an unwell patient and health care professionals working efficiently as a team to manage Tom's deteriorating condition. What I did notice was that members of the MET only spoke to each other and not to Tom. They were also using terminology that I doubt Tom would have understood. Once Tom's condition became stable, most members of the MET exited the room with minimal interaction with him. Before leaving I overheard a ward nurse speaking with Tom, checking on his wellbeing while a doctor wrote in this chart.

Observing Tom's MET review was powerful. I reflected on the event and thought about my usual role and focus when being part of the MET. My usual role within the MET is a leadership position and my focus is on ensuring the team works efficiently to manage the patient's deteriorating condition, but in Tom's case, I observed a different side. I was concerned by the lack of therapeutic communication with Tom and wondered what he thought and how he felt. I wondered if that is how I treat patients when I am part of the MET.

About six weeks later, I was working at triage and a familiar face sat in front of me, it was Tom. He recognised me and began telling me he did not feel well and was scared it was the same as last time. He had spent almost three weeks in hospital and was receiving support through cardiac rehabilitation as an outpatient. Because of his diagnosis and previous presentation, I took Tom into the resuscitation bay for assessment. As I was assisting Tom to change into a hospital gown, he was explaining his symptoms and expressed his fear at presenting back to the hospital. I asked if he remembered the emergency call on the ward, which he did. He recalled feeling unwell, scared and many people being in his room. This time, Tom's admission was not critical as it was previously, and he was admitted for observation only. Not long after this, I left the hospital for a six-month working holiday interstate before returning to take up a teaching position in higher education. I regularly think of Tom and wonder how he recovered and if his experience affected him in anyway.

Since caring for Tom, it has opened my eyes to see the deteriorating patient as not just a condition that requires an efficient team to manage their physiological condition. I began thinking and wondering what it is like for a patient to be cared for during a MET encounter and how this experience may impact their quality of life. Hence, my interest in patients' experiences of acute deterioration and MET encounter.

1.4 Background to the study

In today's society, health services are treating an increasing proportion of patients who are at risk of becoming seriously ill whilst in hospital due to complex chronic medical conditions (Chung et al., 2020; Guinane et al., 2018; Schoen et al., 2009). The increasing demand for hospital beds and shorter hospital stays, along with an ageing population, have resulted in increased patient acuity which can compromise patient safety (Australian Institute of Health and Welfare [AIHW], 2008; Chung et al., 2020; Guinane et al., 2018). It is estimated that adverse events whilst in hospital has resulted in 23 million disability adjusted life years, increased hospital length of stay, decreasing quality of life, and increasing morbidity and mortality (Forster et al., 2003; Guinane et al., 2018; Vincent et al., 2001). An adverse event is defined as "an injury that is caused by medical management, not the disease process, and has led to a prolonged hospital stay or disability at discharge." (Woods et al., 2005, p. 156)

Hospitalised patients with multiple health problems are susceptible to rapid physiological deterioration (Buykx et al., 2012; Liaw et al., 2016). Considerable efforts have been made to identify and understand how health systems respond to patient deterioration (Australian Commission on Safety and Quality in Health Care, 2012; Beaumont et al., 2008; Guinane et al., 2018). To improve the recognition and management of patient deterioration rapid response teams (RRTs) were introduced in order to reduce cardiorespiratory arrest and mortality rates (DeVita et al., 2006). RRTs in Australia are commonly known as medical emergency teams (METs) and by 2005, 65% of Australian intensive care equipped hospitals had an active MET system in place (Guinane et al., 2018; Jones et al., 2009). In an Australia study conducted by Jones et al. (2009), the authors explored the literature to assess if RRT and METs improve patients' outcomes. Of the 14 studies included in the review, all reported an improvement in patient outcomes associated with the introduction of a RRT or MET. Along with the introduction of RRT and METs, observation and response charts such as 'Track and Trigger' and 'Between the Flags' observation and response charts have been introduced to allow recording of patient observations and specifies actions to be taken in response to acute deterioration (ACQSHC, 2020). Credland et al., (2020) conducted a systematic review to examine international research relating to the relationship between Early Warning Track and Trigger Tools and patient outcomes. The review reported improved patient outcomes due to a decrease in cardiopulmonary arrest, mortality, serious adverse events and intensive care/high dependency unit admission following the use of Early Warning Track and Trigger Tools (Credlin et al., 2020). This was similar findings to Alam et al., (2014) who identified that Early Warning Track and Trigger Tools significantly decreased intensive care/high dependency admissions as well as a positive effect on documentation of vital sign parameters.

Patient experiences and satisfaction have become central targets for quality improvement in the healthcare system (ACQSHC, 2017; Chung et al., 2020; Lah et al., 2017). In a study conducted by Glickman et al., (2010), health service efficiency and improved clinical outcomes were found to be associated with better patient experiences. The literature suggests that despite an emphasis on providing patients with an optimal experience, health care services may fall short (Chung et al., 2020; Jha et al., 2008; Rozenblum et al., 2013). Although health care professionals recognise the importance of person-centred care, they acknowledge that the disease is often put before the person (Guinane et al., 2018; Ekman et al., 2011). Azad et al., (2016) explored the perspectives of older adults with heart failure and suggest that poor experiences could be dramatically improved by simple organisational and process changes, rather than complex clinical mechanisms. Understanding the perspectives of the patient is crucial for the development of these organisational and process changes, leading to an optimal patient experience (Azad et al., 2016). In a review conducted by Lah et al., (2017), the researchers explored patients' experiences of intensive care compared to their overall hospital experience. The authors found that for both patient and family members, the experiences of critical illness was the most clinically intense part of their hospital admission (Lah et al., 2017). The experience of acute clinical deterioration is complex and unique, as well as being a difficult experience for all of those involved (ACSQHC, 2012; Chung et al., 2020). However, little is known about this experience from the patient's perspective.

Admission to hospital is considered a stressful experience for patients (Fiori et al., 2017; Meister et al., 2016). According to Fiori et al., (2017), stress as well as the environment in which they are cared for has a significant impact on how patients perceive their hospital experience. Studies have shown that psychological stress responses have a substantial and clinically relevant impact on healing and increased hospital admissions (Gouin & Kiecolt-Glaser, 2011). A scoping literature review on the topic of experiences of acute deterioration and critical illness identified studies that had explored nurses' and family members' experiences (Cioffi, 2000; Douw et al., 2015; Eggenberger & Nelms, 2007) but not patients. Therefore, patients' experiences of their own acute physiological deterioration, and how their experience may influence their everyday existence, deserves exploration.

A qualitative study of 33 participants was conducted in 2015 with part of the study examining the experiences of patients who had a period of clinical deterioration and received a MET review (Guinane et al., 2018). The participants, all patients, described their experiences relating to three themes: patient knowledge of their body, communication and clinicians' trust and expectations (Guinane et al., 2018). Participants were concerned that they were often unaware of why certain clinical interventions were taking place but felt too unwell to communicate prior or during their MET review (Guinane et al., 2018). Some participants stated that the clinical deteriorated was significant enough to alter their cognition and capacity to communicate (Guinane et al., 2018). Therefore, the detection of deterioration relied upon the nurse to assess and interpret patient changes without any guidance from the patient as to how they felt (Guinane et al., 2018).

In health care, the common view is health care professionals are well equipped to address the needs of the deteriorating patient. But, in the current rhetoric of patient safety and quality improvement the absence of the patients' voice in the acute deterioration literature is significant (Chung et al., 2020; Kenward et al., 2017).

1.5 Purpose and aims of the study

The purpose of this study was to generate theory about the processes patients engage in when experiencing acute deterioration and MET encounter. The specific aim of the study was:

- To explore and develop an in-depth understanding of patients' experiences of acute deterioration and MET encounter.

1.5.1 Research question

The following research question guided the methodological approach to the study:

> What processes occur as patients experience acute clinical deterioration and MET encounter?

1.5.2 Objectives

The objectives of this research were to:

- Generate theory about the processes patients engage in when experiencing acute clinical deterioration and MET encounter.
- Provide patients with a voice to tell their story of what it is like to experience acute clinical deterioration and MET encounter.

- Inform health care professionals about patients' experiences.
- Inform health policy to guide consumer reporting of patient deterioration required by national safety and quality health-care service standard across the world.
- Identify recommendations to assist healthcare services to develop strategies to support patients.

1.6 Study Design

A qualitative research methodology, constructivist grounded theory (CGT), was used to explore patients' experiences of acute deterioration and MET encounter. Influenced by symbolic interactionism, CGT methodology is appropriate when there is little known about the area of research and when the researcher aims to generate a theory with explanatory power (Birks & Mills, 2015). Grounded theory embraces the use of a vast array of data sources to understand how research participants construct and define their reality through interactions (Charmaz, 2014). Glaser (2002) states that 'All is Data', that is, everything that is learnt in the research setting about the research topic serves as data. The choice of data collection methods for this study was guided by the research questions and chosen methodology which are discussed in greater detail in chapters three and four of this thesis. Participants in this study were hospital patients who had experienced acute deterioration of their physiological condition leading to a MET encounter. Data were collected through in-depth semi-structured, one-on-one interviews with 27 patients across a range of clinical settings.

1.6.1 Data Analysis

Grounded theory (GT) is a rigorous method of conducting research in which conceptual frameworks or theories are constructed through building inductive theoretical analysis from data (Charmaz, 2014). Data analysis in GT "involves specific procedures which, when applied appropriately and with vigilance will result in theory that is rigorous and well-grounded in the data" (Lawrence & Tar, 2013, p. 32). For this study and keeping with the principles of GT, concurrent data collection and analyses occurred along with constant comparative analyses and theoretical sampling to ensure rigour (Charmaz, 2014). In accordance with Charmaz's (2014) CGT approach, data were analysed using initial, focused and theoretical coding. Memo writing is a crucial method in grounded theory and was used throughout the research process to "keep the researcher involved in the analysis and assist to increase the level of abstraction of their ideas" (Charmaz, 2014, p. 343). Once theoretical categories reached saturation, the conceptual relationships between the categories were explored, and a substantive theory, *Unravelling a complex experience: Contextualising patients' experiences of acute deterioration and Medical Emergency Team (MET) encounter* was constructed.

1.7 Significance of the study

This research is significant as the findings will be the first to generate a substantive theory focusing on patients' experiences of acute deterioration and MET encounter. Healthcare professionals will be better placed to provide relevant, contextual and patient-specific care to those experiencing acute deterioration as well as during and after the MET encounter. Over the last few decades, there have been international concerns in relation to the recognition and management of patient deterioration. This has resulted in a considerable body of evidence known as the 'failure to rescue' literature (Cooper et al., 2016). However, the missing link appeared to be a lack of published research into the actual meanings of experiences of the deteriorating patient and how these experiences may impact the person's everyday existence. This research gives context to the current 'failure to rescue' evidence by informing healthcare professionals and organisations about what it is like to experience acute deterioration from the perspective of the patient, including patients' needs, how to meet those need and any long term impacts. The use of the emergent theory from this research could also be extended to provide a richer understanding of the phenomenon to assist future research such as, person-centred care throughout all phases of acute deterioration and the interaction between MET's and patients.

One method of data collected was implemented in this research to allow participants to describe their experiences and assess their emotional processing following their MET encounters. The data collection method was in-depth semi-structured, one-on-one interviews. The interviews were used to encourage un-anticipated statements and stories to emerge, as well as allowing new leads to be explored. This method provided a unique insight into the experiences of this group of patients, the insights were richer, deep and meaningful. This research is significant as it gives patients who have experienced a unique clinical event a voice; a voice to which health care services and policy makers must listen. To have a positive impact, health care professionals must have a better understanding of the complexities associated with acute deterioration and the problems that patients face during and after their MET encounter. Acute deterioration is unique, extensive and complex as well as being a difficult experience for those involved (ACSQHC, 2012; Chung et al., 2020). The patient's experience is essential in gaining this understanding (Hashem et al., 2016).

1.8 Thesis Structure

This thesis consists of nine chapters. Chapter One has introduced the reader to the study and outlined the research aim, research question, objectives and the context of the study. Chapter Two presents a detailed and integrated background scoping literature review on patients' experiences of acute deterioration. In Chapter Three, a discussion on the methodological basis and its philosophical underpinning is provided. In Chapter Five, the study findings are presented. The beginning of this chapter presents an overview of the findings expressed through a diagrammatic expression of the findings, which give rise to the theory. Chapter Six presents a manuscript discussing the constructed theory and the associated model. In Chapter Seven, contextual factors that influenced patients' experiences of acute deterioration and MET encounter are presented. An overall discussion of the findings in the broader context is provided in Chapter Eight, as well as study implications and recommendations for clinical practice, education and research. Study limitations are also outlined in this chapter. Finally, in the concluding chapter, the study is summarised, and the evaluation criteria used to evaluate the contrasted theory are discussed.

The published journal article included in the thesis has been through a blinded review process prior to publication. Another journal article has been accepted with minor changes and the remaining manuscript is currently under review. Readers may find some repeated ideas between the manuscripts, which was necessary to provide adequate explanation and background to the journal readers. In addition, following journal word limits, articles may appear lengthy and may vary in citation style. According to Federation University guidelines, published articles are presented in their submission or publication format.

1.9 Summary of Chapter One

Chapter One has presented an introduction to the research study. The study background and study origins were discussed. To set the context for the research, a discussion of relevant terminology such as patient experience, acute deterioration and medical emergency team was provided. My professional experience caring for a patient before, during and after a MET review was described and linked to the impetus for this research. The research questions, aims, objectives and significance of the research were explained. The next chapter further establishes the research context by presenting a scoping literature review focusing on patients' experiences of acute deterioration and the psychological management.

CHAPTER TWO

Background

Chapter Two: Patients' experiences of acute deterioration – A Review of the Literature

2.1 Introduction

The previous chapter provided an overview and discussion of the study's purpose and context. Chapter Two provides an in-depth exploration of the context in which the study is positioned. An initial review of the literature was undertaken to explore current knowledge and identify gaps in the existing literature.

2.2 Chapter Content

There is much debate about the use of literature in the initial stages of a grounded theory study (Birks & Mills, 2015). When using grounded theory, Glaser (1992) advocated for delaying the literature review until after analysis is complete. Glaser (1992) argued that a preliminary literature review will cause the researcher to impose existing theories or knowledge on the study processes or outcomes (Birks & Mills, 2015). However, Glaser (1992) encouraged grounded theorists to engage with the literature from the beginning but outside the topic area. In contrast, Charmaz (2006; 2014) and many grounded theorists (Clarke, 2005; Bulmer, 1984; Corbin & Strauss, 2008; Dey, 1999; Dunne, 2011; Laydner, 1998; Thornberg, 2011; Urquhart, 2007) have disputed this stance, and instead suggest a preliminary literature review can enhance theoretical sensitivity and stimulate relevant questioning. Urquhart (2007) argues that reviewing the literature when undertaking a grounded theory study is an effective means of familiarising the researcher to concepts, although it is imperative that grounded theorists use strategies to avoid imposing preconceived ideas and biases onto the data. The strategies used throughout the research process, in the current study, are detailed in the concluding chapter.

PAPER 1:

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The aims of this scoping review was to explore what is known about the experience of acute deterioration from the perspective of the patient. International, peer-reviewed studies and grey literature published between the years of 2000-2019 were considered.

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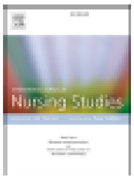

Patients' experiences of acute deterioration: A scoping review

Catherine Chung[a,*], Lisa McKenna[a,b], Simon J. Cooper[a]

[a] Nursing and Healthcare Professions, Federation University Australia, Northways Rd., Churchill, Victoria 3842, Australia
[b] School of Nursing and Midwifery, La Trobe University, Bundoora, Victoria 3086, Australia

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ABSTRACT

Background: Patient experience is recognised as a means of assessing healthcare delivery with organisations in many countries now gathering patient experience or satisfaction data. It is well documented that the benefits of improving a patients' experience include increased satisfaction, reduced length of stay, improved patient outcomes and reduction of costs. The experience of acute clinical deterioration is unique, extensive and complex as well as being a difficult experience for all involved. However, little is known about this experience from the patient's perspective.

Aim: To explore what is known about the experiences of acute deterioration from the perspective of the patient.

Design: A scoping review of international, peer-reviewed research studies and grey literature published between the years of 2000 and 2018. This review was guided by the three-step search strategy recommended by the Joanna Briggs Institute (JBI).

Data sources: A range of databases were searched, including CINAHL, Medline, Health Source, Joanna Briggs Institute, PsycINFO, Embase via Ovid, Cochrane library, Ovid Emcare, Scopus as well as grey literature, reference lists and the search engine Google Scholar.

Review methods: Joanna Briggs Institute (JBI) scoping review framework was utilised to identify patients' experiences of acute deterioration. Ten databases were searched, and 249 articles were retrieved. After screening the titles and abstracts, 102 articles were assessed in full text for eligibility, and finally 23 articles were further analysed and synthesised using inductive thematic analysis.

Results: 19 qualitative studies, three quantitative and one mixed methods study met the inclusion criteria. Seven key themes emerged related to patients' experience of acute deterioration: (1) transformation of perception: memories of factual events; (2) psychological transformation: emotional distress and well-being; (3) physiological transformation: physical distress; (4) facing death; (5) the severity of acute deterioration: from the perspective of the patient; (6) relationship with healthcare professionals and the clinical environment; and (7) the value of relationships: the support of family and friends.

Conclusions: Participants had considerable recall of their experiences and hospital admissions. The themes highlight the important issues patients face during their own acute physiological deterioration. This review has highlighted that further research is needed to specifically explore the patients' experience of acute deterioration and the emergency management they receive, for example from a hospital's rapid response team (RRT) or medical emergency team (MET).

What is already known about the topic?

- Internationally, patient experience is recognised as a means of assessing healthcare delivery with many countries now gathering patient experience or satisfaction data.
- It is well documented that the benefits of improving a patient's experience include increased satisfaction, reduced length of stay, improved patient outcomes and reduction of costs.
- The experience of acute clinical deterioration is unique, extensive and complex for all those involved. However, little is known about this experience from the patient's perspective.

What this paper adds

- Patients experience perceptual, emotional and physical distress during acute clinical deterioration.
- Patients are involved to some degree in the process of recognising their own physical signs of acute deterioration. Patients may not understand the severity but typically know that they are unwell and require treatment.

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* Corresponding author.
E-mail address: catherine.chung@federation.edu.au (C. Chung).

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- During acute clinical deterioration, a positive relationship between patients and healthcare professionals is crucial and the first step towards their recovery.

1. Background

In today's society, health services are treating increasing numbers of patients with complex medical conditions who are at risk of acute deterioration and serious adverse events during hospitalisation (Guinane et al., 2018; Vorwerk and King, 2016; Schoen et al., 2009). Patient safety, and ensuring that patients who deteriorate receive appropriate and timely care, is a global concern (Australian Commission of Safety and Quality in Health Care [ACSQHC], 2017). It has been reported that in high-income countries, patient safety is compromised by the increasing demands for hospital beds and shorter hospital stays, along with an ageing population (World Health Organisation [WHO], 2017; Australian Institute of Health and Welfare [AIHW], 2008). Whereas, in low- and middle-income countries, patient safety is reportedly affected by factors such as understaffing, inadequate structures, overcrowding, lack of health care commodities and shortage of basic equipment, as well as poor hygiene and sanitation (WHO, 2017). Acute deterioration is defined as "physiological, psychological or cognitive changes that may indicate a worsening of the patient's health status; this may occur across hours or days" (ACSQHC, 2017, p. 67). An adverse event is defined as an unintended injury or complication resulting in a prolonged hospital stay, disability at the time of discharge or death, and is caused by health care management rather than by the patient's underlying disease process (de Vries et al., 2008). In a report published by WHO (2017) on patient safety, it was estimated that there were 421 million hospitalisations annually around the world, with approximately 42.7 million adverse events occurring during those hospitalisations.

Internationally, patient experience is recognised as a means of assessing healthcare delivery with many countries now gathering patient experience or satisfaction data (Edwards et al., 2014). In Australia, the National Safety and Quality Health Service (NSQHS) standards were developed to protect the public from harm and improve quality of health service provision (ACQSHC, 2012; 2017). The eight standards provide a quality assurance mechanism that tests whether relevant systems are in place to ensure that expected standards of safety and quality are met (ACQSHC, 2017). Along with *Standard 8 –Recognising and Responding to Acute Deterioration*, patient experiences and satisfaction have become central targets for quality improvement across the healthcare system (ACQSHC, 2017; Soowhan et al., 2017). In the UK, the National Institute for Health and Care Excellence (NICE) developed quality standards to prioritise areas for quality improvement in health and social care (NICE, 2018). The quality standard *Patient experience in adult National Health Services (NHS)* aims to ensure patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty (NICE, 2018).

It is well documented that the benefits of improving a patient's experience include increasing satisfaction through reduced length of stay, improved outcomes and reduction of costs (Edward et al., 2014; Wolf et al., 2012; Epstein et al., 2010). The 2017 NSQHS Standards state in *Standard 2 – Partnering with Consumer Standard* that a positive experience for patients is linked to effective partnerships, high quality health care and improved patient safety (ACSQHC, 2017). In this field, Soowhan et al. (2017) conducted a review of patients' perceptions of the quality of inpatient care by comparing intensive care and overall hospitalisation, identifying that the experience of critical illness was the most clinically intense part of a hospitalisation for both patient and family members. The experience of acute deterioration is unique, extensive and complex as well as being a difficult experience for all involved (ACSQHC, 2012). However, little is known about this experience from the patient's perspective.

The main research question for this scoping review was: 'What is known about the experiences of acute deterioration from the perspective of the patient?' Despite a predominant view in health care that health care professionals are well equipped to address the needs of deteriorating patients, absence of the patient's voice in the research literature is particularly pertinent in the current rhetoric of quality improvement and safety (Rier, 2000; Drenth, 2013; Guinane et al., 2018; Kenward et al., 2017). Accordingly, this review is a valuable and important addition to international knowledge. It aims to provide a broad overview and to map major themes underpinning patients' experiences of acute deterioration to enhance patient support, improve patient experiences and determine future research needs.

2. Method

A scoping literature review is an iterative process of summarised literature in the field to identify the breadth and depth of a concept of issue (Levac et al., 2010). This scoping review investigated the breadth of research on the topic of patients' experiences of acute deterioration, generating an intellectual overview of what is known about the topic. The review was conducted according to an adapted framework proposed by Joanna Briggs Institute (JBI) (Peters et al., 2015). This framework builds on the previously established guidelines by Arksey and O'Malley (2005). In addition, the PRIMSA statement for systematic review protocols guided this review (Moher et al., 2015). For example, as proposed in the statement, a flow chart was created (Fig. 1) and the methodological quality of included articles was assessed.

2.1. Search strategy

The literature search for this scoping review was carried out between January and December 2018 and aimed to find both published and unpublished studies. As proposed in the JBI manual (Peters et al., 2015), the search strategy comprised three subsequent steps. The first step was an initial limited search of MEDLINE (plus), CINAHL and Google Scholar followed by analysis of words contained in the titles and abstracts of retrieved papers, and index terms used to describe the article. A second search was conducted using all identified keywords and index terms across all included databases. Thirdly, reference lists of identified reports and articles were searched for additional studies.

The following databases and search engine were searched: CINAHL, Medline, Health Source, Joanna Briggs Institute, PsycINFO, Embase via Ovid, Cochrane library, Ovid Emcare, Scopus and Google Scholar. The search for unpublished studies was conducted in the following sources: for theses and dissertations: ProQuest Dissertations and Theses, Ethos, DART Europe and Trove. For conference papers: Conference Papers Index, Conference Proceedings Citation Index. For guidelines: Guideline.gov, NICE, CMA Infobase, JBI Database of Systematic Reviews and Implementation Reports. For grey literature: OpenGrey Repository, Google and websites of selected organizations were examined. The keywords and subject headings used to search these databases are listed in Table 1.

2.2. Study selection process

The inclusion criteria for selecting articles was established (Table 2). Studies involving a subset of relevant study participants were considered for inclusion if results were specified for the population of interest. We sought studies conducted worldwide that were published in English.

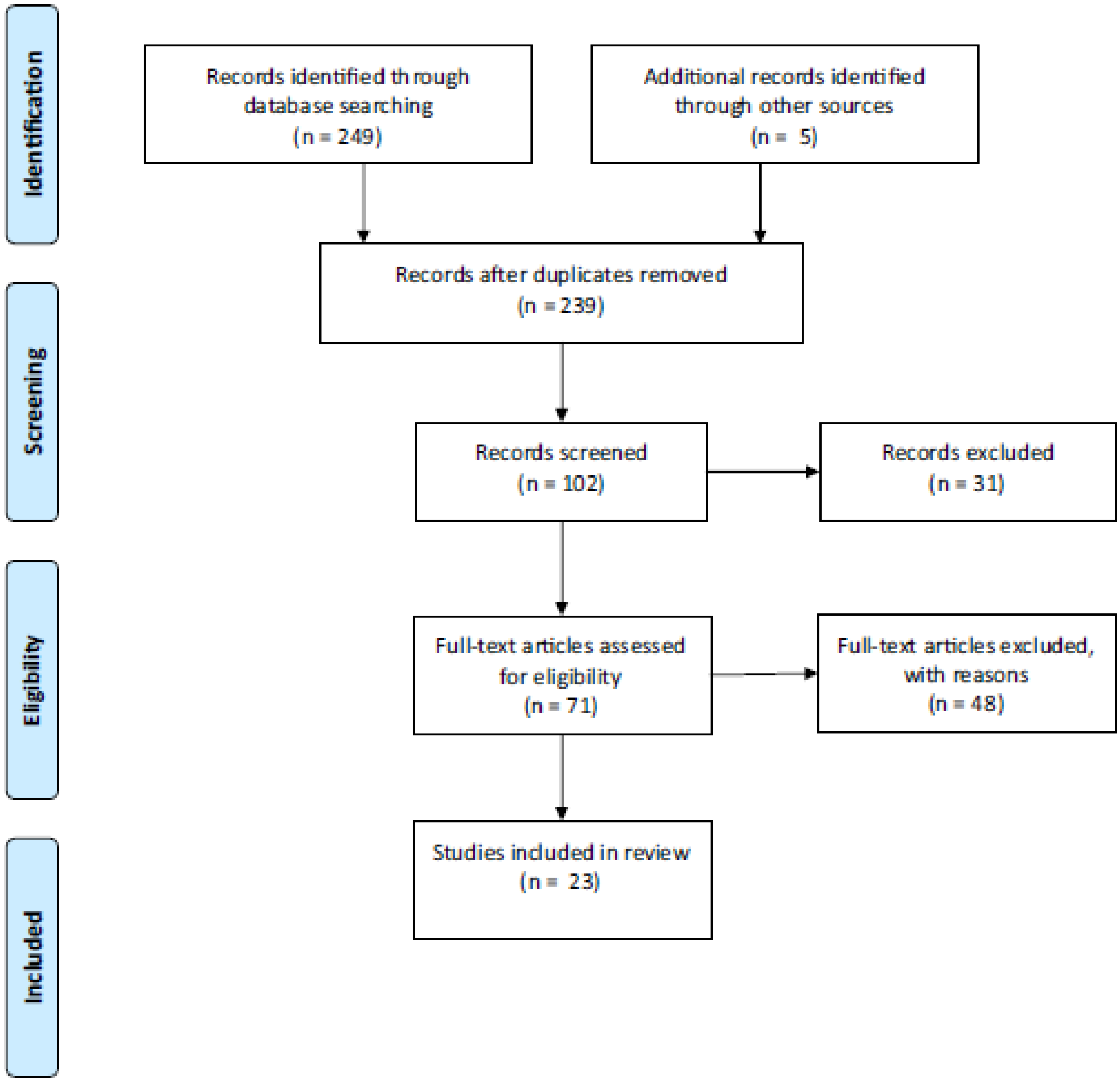

Fig. 1. Identification and selection of studies.

Table 1
Keywords and subject headings used during the search.

Search Terms
"patient* perspective*" OR "patient* experience*" OR "patient* perception*" OR "patient* opinion*" OR "patient* attitude*" OR "patient* view*" AND "acute deterioration" OR "clinical deterioration" OR "medical emergency team*" OR "rapid response team*" OR "rapid response system*".
"consumer* perspective*" OR "consumer* experience*" OR "consumer* perception*" OR "consumer* opinion*" OR "consumer* attitude*" OR "consumer* view*" AND "acute deterioration" OR "clinical deterioration*" OR "medical emergency team*" OR "rapid response team*" OR "rapid response system*".
"person* perspective*" OR "person* experience*" OR "person* perception*" OR "person* opinion*" OR "person* attitude*" OR "person* view*" AND "acute deterioration" OR "clinical deterioration*" OR "medical emergency team*" OR "rapid response team*" OR "rapid response system*".

Table 2
Inclusion and exclusion criteria for selected articles.

Inclusion criteria	Exclusion criteria
• Peer-reviewed, primary research. • Published in English. • Focusing on patients' (*population*) experiences of acute physiological deterioration (*concept*) in the hospital setting (*context*). • Published between January 2000 and December 2018.	• Not peer-reviewed, primary research. • Not written in English. • Literature that did not include empirical data (letters, editorials, news etc.).

Initially, the first author screened titles and abstracts for possible eligibility. To increase reliability, this process was carried out in collaboration with the research team (C.C, L.M & S.C). All authors independently screened a random selection of 25 titles and abstract, any variances were discussed and a consensus was reached. After reaching consensus, author C.C. continued the title-abstracts screening process. Once the screening process was complete, eligible records were obtained as full texts. If full texts was unavailable via online access, the article/s were requested via inter-library loan service. The research team assessed the eligibility of a random selection of 20 articles and once full agreement occurred, the first author continued with full-text assessment. The final list of included articles was evaluated and verified by the research team.

2.3. Data charting, item extraction and synthesis

A data charting form, adapted from JBI Methodology for Scoping Reviews (The Joanna Briggs Institute, 2015), was used to record data extracted from included articles. To answer the scoping review question, the authors considered what particular data should be extracted. After much consideration and consultation between all authors, the lead author extracted the following data from each article: study design and purpose, country of origin, sample method, main findings and limitations. A quality score was given to each article once the quality appraisal process was complete. To ensure rigour and authenticity, the two other authors reviewed the extracted data before all authors undertook a final check.

Inductive thematic analysis was used across the studies to identify key emerging themes (Braun and Cohen, 2012). The findings from each of the papers were reviewed and compared until preliminary themes were identified (Vaismoradi et al., 2013). The preliminary themes were discussed amongst all authors as the data extraction and thematic synthesis evolved; the thematic synthesis was then updated and altered between various drafts of the review.

2.4. Quality appraisal

While critical appraisal is not a compulsory measure in Peters et al. (2015) scoping review framework, Brien et al. (2010) state that the lack of quality assessment makes results of a scoping review more challenging to interpret. Grant and Booth (2009) imply the lack of quality assessment limits the uptake of scoping study findings into policy and practice. Therefore, the primary research articles were critically appraised using the Critical Appraisal Skills Programme (CASP) criteria for evaluating qualitative (CASP, 2018a) and quantitative (CASP, 2018b) research. This instrument consists of 10 questions to assess quality of qualitative studies and 12 questions for quantitative studies. It cannot appraise mixed methods studies. Therefore, the Mixed Methods Appraisal Tool (MMAT) developed by Pluye et al. (2011) and revised by Hong et al. (2018) was used to evaluate the mixed methods study. In addition, the CASP is not appropriate to appraise observational studies, therefore, the *REporting of studies Conducted using Observational Routinely-collected health data* (RECORD) checklist (Benchimol et al., 2015), endorsed by the Equator Network was used to appraise the quantitative observational study (Dziadzko et al., 2017) included in this review.

3. Results

3.1. Literature search

Across the ten databases, a total of 249 abstracts were sourced. Five additional records were identified through grey literature. Following removal of duplicates, 231 records remained. Titles were screened for relevance, leaving 102 for further review. Of these, 71 were considered directly related to the research questions and full texts were reviewed. A further 48 were removed at this point following application of inclusion criteria, leaving 23 papers for the final review (Fig. 1).

3.2. Article information

Table 3 provides a summary of the included studies. Of the 23 studies included in the review, nineteen were qualitative (Adamson et al., 2004; Alpers et al., 2012; Cox et al., 2009; Cypress, 2011, 2015; Engstrom et al., 2013; Guinane et al., 2018; Johnson et al., 2006; Karlsson et al., 2012; Kean et al., 2016; Lof et al., 2006; Lof et al., 2008; Mylen et al., 2016; Olsen et al., 2017; Papathanassoglou and Patiraki, 2003; Rosa et al., 2017; Samuelson, 2011; Tembo et al., 2012; Wang et al., 2008), three were quantitative studies (Dziadzko et al., 2017; Sukantarat et al., 2007; Zetterlund et al., 2012) and one used mixed methodology (Hofhuis et al., 2008).

Of the qualitative studies, all used individual interviews to gather information. The methods of the quantitative studies involved questionnaires conducted at three and six months post-ICU discharge (Sukantarat et al., 2007) and six to 18 months after the trauma occurred with a five-year follow-up questionnaire (Zetterlund et al., 2012). The methods used in the mixed methods study were individual interviews and questionnaires.

Included studies originated from various countries, with seven undertaken in Sweden, four in Australia and USA, two in Norway and the UK, and one each in China, Greece, Italy and The Netherlands. The majority (20) were from nursing, with one each from medicine, psychiatry and psychology. All studies referred to, or involved, patients cared for in a critical care unit (CCU) or intensive care (ICU), except Guinane et al. (2018) and Rosa et al. (2017) who studied general ward patients.

3.3. Methodological quality appraisal

All of the articles were included in the quality appraisal. Table 3 identifies the proportion of satisfied criteria met (%) for each article included in this review. Seven qualitative studies (Alpers et al., 2012; Cypress, 2011; Johnson et al., 2006; Karlsson et al., 2012; Olsen et al., 2017; Tembo et al., 2012; Wang et al., 2008) fulfilled all CASP criteria. Whereas, 10 studies (Adamson et al., 2004; Cox et al., 2009; Engstrom et al., 2013; Guinane et al., 2018; Kean et al., 2016; Lof et al., 2008; Lof et al., 2006; Mylen et al., 2016; Rosa et al., 2017; Samuelson, 2011) met all but one criteria: *adequately describe the relationship between the researchers*. The remaining studies (n=2) did not meet two of the CASP criteria: *adequately describe the relationship between the researchers* and *rigorous data analysis* or *ethical issues taken into consideration*. The quantitative studies (Sukantarat et al., 2007; Zetterlund et al., 2012) appraised using the CASP criteria met all but one criteria: *can the results be applied to the local population?* The quantitative observational study (Dziadzko et al., 2017) appraised using the RECORD checklist met all but three criteria: *potential source of bias identified the extent investigators had access to the database population used to create the study population* and *funding source*. The mixed methods study (Hofhuis et al., 2008) met all of the MMAT criteria but one: *is the integration of qualitative and quantitative data relevant to address the research question*.

3.4. Narrative summary of themes

Concepts reflecting the experiences of acute deterioration from the perspective of the patient were clustered into the following

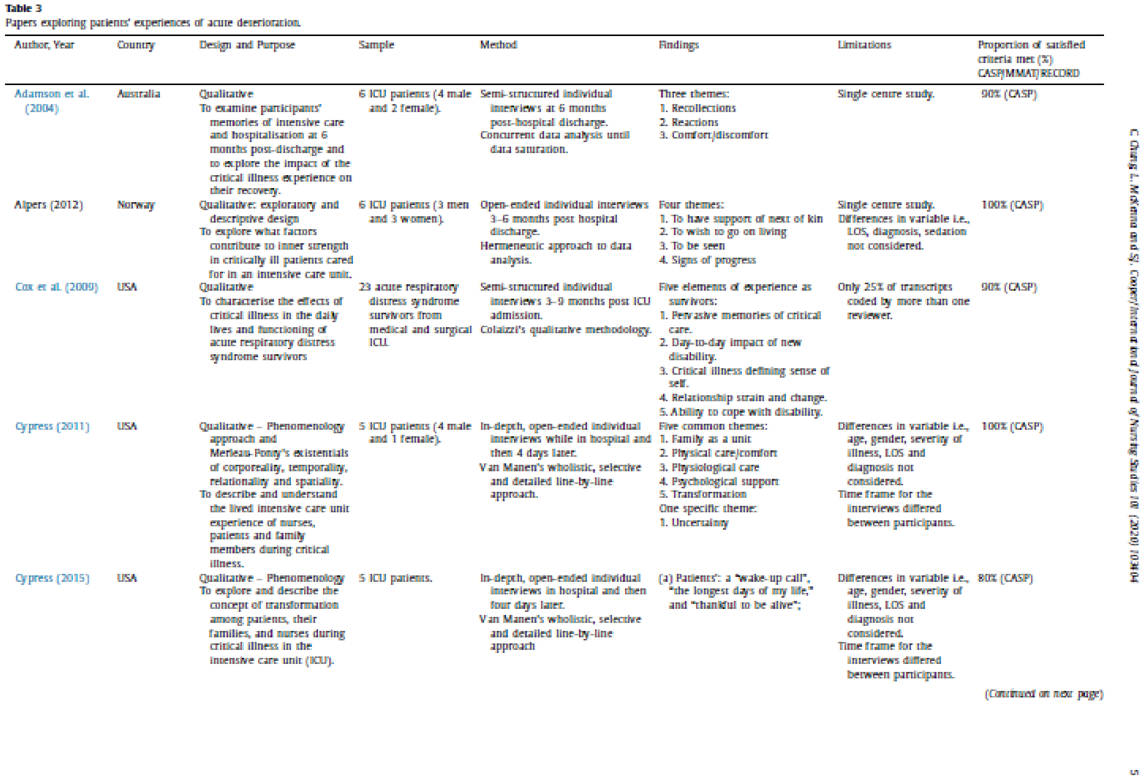

Table 3
Papers exploring patients' experiences of acute deterioration.

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP/MMAT/RECORD
Adamson et al. (2004)	Australia	Qualitative To examine participants' memories of intensive care and hospitalisation at 6 months post-discharge and to explore the impact of the critical illness experience on their recovery.	6 ICU patients (4 male and 2 female).	Semi-structured individual interviews at 6 months post-hospital discharge. Concurrent data analysis until data saturation.	Three themes: 1. Recollections 2. Reactions 3. Comfort/discomfort	Single centre study.	90% (CASP)
Alpers (2012)	Norway	Qualitative: exploratory and descriptive design To explore what factors contribute to inner strength in critically ill patients cared for in an intensive care unit.	6 ICU patients (3 men and 3 women).	Open-ended individual interviews 3–6 months post hospital discharge. Hermeneutic approach to data analysis.	Four themes: 1. To have support of next of kin 2. To wish to go on living 3. To be seen 4. Signs of progress	Single centre study. Differences in variable i.e., LOS, diagnosis, sedation not considered.	100% (CASP)
Cox et al. (2009)	USA	Qualitative To characterise the effects of critical illness in the daily lives and functioning of acute respiratory distress syndrome survivors	23 acute respiratory distress syndrome survivors from medical and surgical ICU.	Semi-structured individual interviews 3–9 months post ICU admission. Colaizzi's qualitative methodology.	Five elements of experience as survivors: 1. Pervasive memories of critical care. 2. Day-to-day impact of new disability. 3. Critical illness defining sense of self. 4. Relationship strain and change. 5. Ability to cope with disability.	Only 25% of transcripts coded by more than one reviewer.	90% (CASP)
Cypress (2011)	USA	Qualitative – Phenomenology approach and Merleau-Ponty's existentials of corporeality, temporality, relationality and spatiality. To describe and understand the lived intensive care unit experience of nurses, patients and family members during critical illness.	5 ICU patients (4 male and 1 female).	In-depth, open-ended individual interviews while in hospital and then 4 days later. Van Manen's wholistic, selective and detailed line-by-line approach.	Five common themes: 1. Family as a unit 2. Physical care/comfort 3. Physiological care 4. Psychological support 5. Transformation One specific theme: 1. Uncertainty	Differences in variable i.e., age, gender, severity of illness, LOS and diagnosis not considered. Time frame for the interviews differed between participants.	100% (CASP)
Cypress (2015)	USA	Qualitative – Phenomenology To explore and describe the concept of transformation among patients, their families, and nurses during critical illness in the intensive care unit (ICU).	5 ICU patients.	In-depth, open-ended individual interviews in hospital and then four days later. Van Manen's wholistic, selective and detailed line-by-line approach	(a) Patients': a "wake-up call", "the longest days of my life," and "thankful to be alive";	Differences in variable i.e., age, gender, severity of illness, LOS and diagnosis not considered. Time frame for the interviews differed between participants.	80% (CASP)

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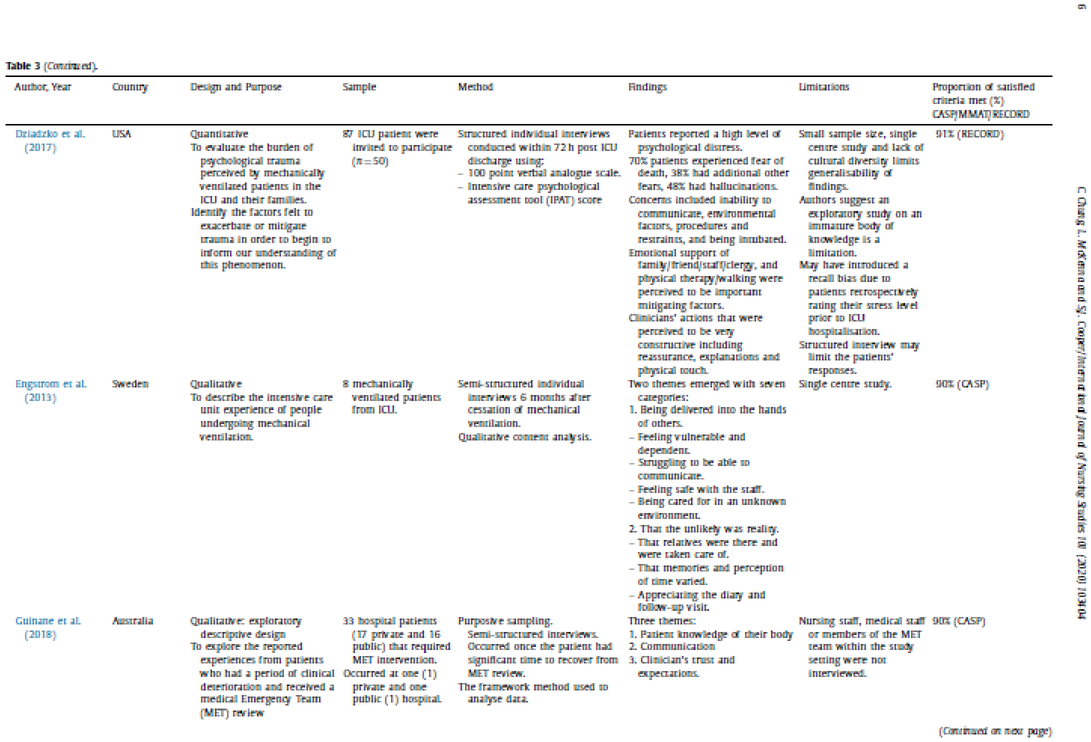

Table 3 (Continued).

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP/MMAT/RECORD
Dziadzko et al. (2017)	USA	Quantitative To evaluate the burden of psychological trauma perceived by mechanically ventilated patients in the ICU and their families. Identify the factors felt to exacerbate or mitigate trauma in order to begin to inform our understanding of this phenomenon.	87 ICU patient were invited to participate ($n = 50$)	Structured individual interviews conducted within 72 h post ICU discharge using: – 100 point verbal analogue scale. – Intensive care psychological assessment tool (IPAT) score	Patients reported a high level of psychological distress. 70% patients experienced fear of death, 38% had additional other fears, 48% had hallucinations. Concerns included inability to communicate, environmental factors, procedures and restraints, and being intubated. Emotional support of family/friend/staff/clergy, and physical therapy/walking were perceived to be important mitigating factors. Clinicians' actions that were perceived to be very constructive including reassurance, explanations and physical touch.	Small sample size, single centre study and lack of cultural diversity limits generalisability of findings. Authors suggest an exploratory study on an immature body of knowledge is a limitation. May have introduced a recall bias due to patients retrospectively rating their stress level prior to ICU hospitalisation. Structured interview may limit the patients' responses.	91% (RECORD)
Engstrom et al. (2013)	Sweden	Qualitative To describe the intensive care unit experience of people undergoing mechanical ventilation.	8 mechanically ventilated patients from ICU.	Semi-structured individual interviews 6 months after cessation of mechanical ventilation. Qualitative content analysis.	Two themes emerged with seven categories: 1. Being delivered into the hands of others. – Feeling vulnerable and dependent. – Struggling to be able to communicate. – Feeling safe with the staff. – Being cared for in an unknown environment. 2. That the unlikely was reality. – That relatives were there and were taken care of. – That memories and perception of time varied. – Appreciating the diary and follow-up visit.	Single centre study.	90% (CASP)
Guinane et al. (2018)	Australia	Qualitative: exploratory descriptive design To explore the reported experiences from patients who had a period of clinical deterioration and received a medical Emergency Team (MET) review	33 hospital patients (17 private and 16 public) that required MET intervention. Occurred at one (1) private and one public (1) hospital.	Purposive sampling. Semi-structured interviews. Occurred once the patient had significant time to recover from MET review. The framework method used to analyse data.	Three themes: 1. Patient knowledge of their body 2. Communication 3. Clinician's trust and expectations.	Nursing staff, medical staff or members of the MET team within the study setting were not interviewed.	90% (CASP)

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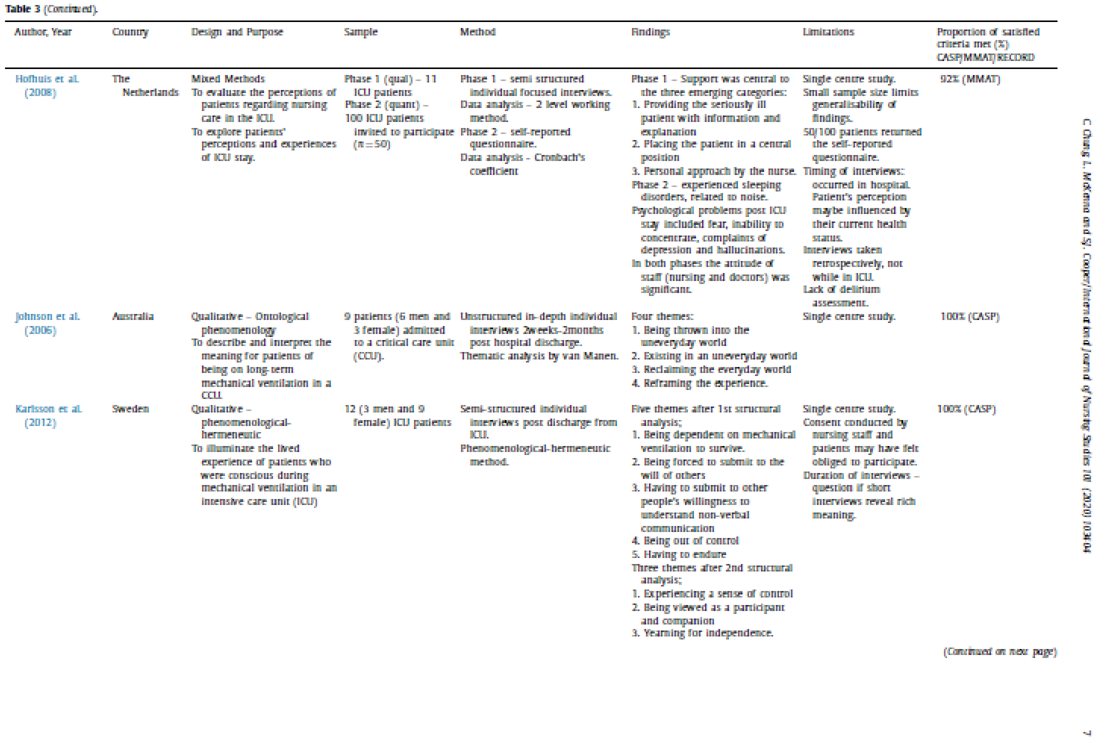

Table 3 (*Continued*).

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP/MMAT/RECORD
Hofhuis et al. (2008)	The Netherlands	Mixed Methods To evaluate the perceptions of patients regarding nursing care in the ICU. To explore patients' perceptions and experiences of ICU stay.	Phase 1 (qual) – 11 ICU patients Phase 2 (quant) – 100 ICU patients invited to participate (n = 50)	Phase 1 – semi structured individual focused interviews. Data analysis – 2 level working method. Phase 2 – self-reported questionnaire. Data analysis - Cronbach's coefficient	Phase 1 – Support was central to the three emerging categories: 1. Providing the seriously ill patient with information and explanation 2. Placing the patient in a central position 3. Personal approach by the nurse. Phase 2 – experienced sleeping disorders, related to noise. Psychological problems post ICU stay included fear, inability to concentrate, complaints of depression and hallucinations. In both phases the attitude of staff (nursing and doctors) was significant.	Single centre study. Small sample size limits generalisability of findings. 50/100 patients returned the self-reported questionnaire. Timing of interviews: occurred in hospital. Patient's perception maybe influenced by their current health status. Interviews taken retrospectively, not while in ICU. Lack of delirium assessment.	92% (MMAT)
Johnson et al. (2006)	Australia	Qualitative – Ontological phenomenology To describe and interpret the meaning for patients of being on long-term mechanical ventilation in a CCU.	9 patients (6 men and 3 female) admitted to a critical care unit (CCU).	Unstructured in-depth individual interviews 2weeks-2months post hospital discharge. Thematic analysis by van Manen.	Four themes: 1. Being thrown into the uneveryday world 2. Existing in an uneveryday world 3. Reclaiming the everyday world 4. Reframing the experience.	Single centre study.	100% (CASP)
Karlsson et al. (2012)	Sweden	Qualitative – phenomenological-hermeneutic To illuminate the lived experience of patients who were conscious during mechanical ventilation in an intensive care unit (ICU)	12 (3 men and 9 female) ICU patients	Semi-structured individual interviews post discharge from ICU. Phenomenological-hermeneutic method.	Five themes after 1st structural analysis; 1. Being dependent on mechanical ventilation to survive. 2. Being forced to submit to the will of others 3. Having to submit to other people's willingness to understand non-verbal communication 4. Being out of control 5. Having to endure Three themes after 2nd structural analysis; 1. Experiencing a sense of control 2. Being viewed as a participant and companion 3. Yearning for independence.	Single centre study. Consent conducted by nursing staff and patients may have felt obliged to participate. Duration of interviews – question if short interviews reveal rich meaning.	100% (CASP)

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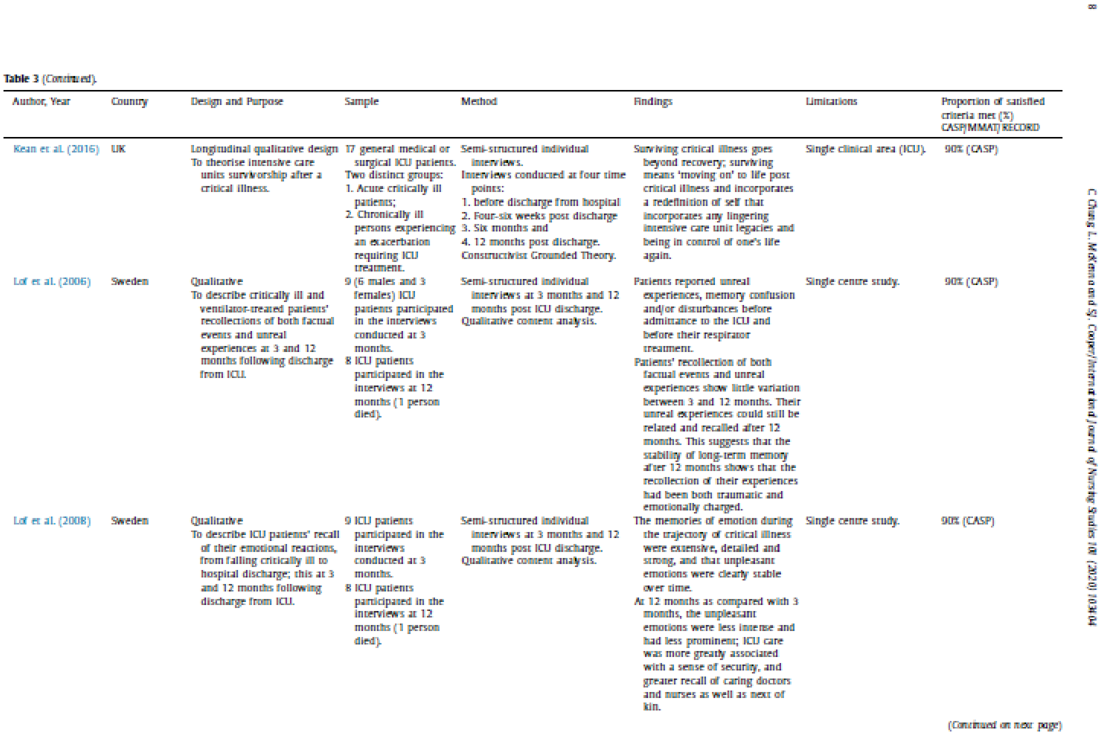

Table 3 (*Continued*).

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP/MMAT/RECORD
Kean et al. (2016)	UK	Longitudinal qualitative design To theorise intensive care units survivorship after a critical illness.	17 general medical or surgical ICU patients. Two distinct groups: 1. Acute critically ill patients; 2. Chronically ill persons experiencing an exacerbation requiring ICU treatment.	Semi-structured individual interviews. Interviews conducted at four time points: 1. before discharge from hospital 2. Four-six weeks post discharge 3. Six months and 4. 12 months post discharge. Constructivist Grounded Theory.	Surviving critical illness goes beyond recovery; surviving means 'moving on' to life post critical illness and incorporates a redefinition of self that incorporates any lingering intensive care unit legacies and being in control of one's life again.	Single clinical area (ICU).	90% (CASP)
Lof et al. (2006)	Sweden	Qualitative To describe critically ill and ventilator-treated patients' recollections of both factual events and unreal experiences at 3 and 12 months following discharge from ICU.	9 (6 males and 3 females) ICU patients participated in the interviews conducted at 3 months. 8 ICU patients participated in the interviews at 12 months (1 person died).	Semi-structured individual interviews at 3 months and 12 months post ICU discharge. Qualitative content analysis.	Patients reported unreal experiences, memory confusion and/or disturbances before admittance to the ICU and before their respirator treatment. Patients' recollection of both factual events and unreal experiences show little variation between 3 and 12 months. Their unreal experiences could still be related and recalled after 12 months. This suggests that the stability of long-term memory after 12 months shows that the recollection of their experiences had been both traumatic and emotionally charged.	Single centre study.	90% (CASP)
Lof et al. (2008)	Sweden	Qualitative To describe ICU patients' recall of their emotional reactions, from falling critically ill to hospital discharge; this at 3 and 12 months following discharge from ICU.	9 ICU patients participated in the interviews conducted at 3 months. 8 ICU patients participated in the interviews at 12 months (1 person died).	Semi-structured individual interviews at 3 months and 12 months post ICU discharge. Qualitative content analysis.	The memories of emotion during the trajectory of critical illness were extensive, detailed and strong, and that unpleasant emotions were clearly stable over time. At 12 months as compared with 3 months, the unpleasant emotions were less intense and had less prominent; ICU care was more greatly associated with a sense of security, and greater recall of caring doctors and nurses as well as next of kin.	Single centre study.	90% (CASP)

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Table 3 (*Continued*).

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP|MMAT|RECORD
Mylen et al. (2016)	Sweden	Qualitative – Interpretive phenomenology To explore the lived experience of conscious patients in neurological intensive care.	11 (4 men and 7 women) ICU patients.	Semi-structured individual interviews. Conducted between two-14 months post discharge. Phenomenological approach to data analysis – the Stevick–Colaizzi–Keens method modified by Moustakas.	Three themes: 1. To feel safe in an unfamiliar situation 2. To experience strains and limitations 3. To be confirmed as a human being.	Single centre study. Quality of interviews could have been affected by interviewer's inexperience. Those that declined to participate could have had a negative experience and therefore the study could lack other dimensions.	90% (CASP)
Olsen et al. (2017)	Norway	Qualitative – exploratory design To investigate how adult patients experience their intensive care stay, their recovery period, and the usefulness of an information pamphlet.	29 ICU patients	Semi-structured individual interviews conducted post ICU discharge and three months after discharge from the hospital. Qualitative content analysis.	Two themes: 1. Being on an unreal, strange journey 2. Balancing between who I was and who I am.	Single centre study. Three ICU nurses conducted interviews which may influence the data with differing interview styles. It may also influence the patient's response as the nurse may care for or have cared for the patient.	100% (CASP)
Papathanassoglou & Patiraki. (2003)	Greece	Qualitative - Interpretive phenomenological design stemming from hermeneutics To explore the lived experience of individual with a past hospitalisation in an intensive care unit, with a focus on dreams.	8 (3 men and five women) ICU patients.	Semi-structured individual interviews using open-ended questions conducted over a two year period. Phenomenological analysis and the hermeneutical cycle of interpretation.	Four themes: 1. Transformation of perception and of the lived-body, time and space 2. Aloneness 3. Death-rebirth 4. Transformation of life.	Single centre study.	80% (CASP)
Rosa et al. (2017)	Italy	Qualitative – A descriptive phenomenological study To explore the experience of patients affected by chronic obstructive pulmonary disease following hospitalisation due to an acute exacerbation event.	12 hospital patients with a recent admission of acute exacerbation of COPD who has been stabilised and preparing for discharge.	In-depth individual interviews over nine months. Colaizzi's descriptive analysis framework.	Four themes: 1. A sense of loss and frustration 2. Hopelessness 3. Uncertainty about the future care 4. The burden they may become on their family. The patients appeared stressed and anxious as a result of the acute event they had experienced.	Single centre study. Did not enquire about the patients' prior knowledge held about their prognosis.	90% (CASP)

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Table 3 (*Continued*).

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP|MMAT|RECORD
Samuelson (2011)	Sweden	Qualitative – descriptive design To describe unpleasant and pleasant memories of the ICU stay in adult mechanically ventilated patients.	250 ICU patients.	Individual interviews using two open-ended questions, 3–4 days after ICU discharge. Qualitative content analysis.	Ten categories emerged, contrasting with each other (five from pleasant and five from unpleasant): 2. Physical distress and relief of physical distress 3. Emotional distress and emotional well-being 4. Perceptual distress and perceptual well-being 5. Environmental distress and environmental discomfort 6. Stress-inducing care and care service.	Limitations in data handling processes due to large amount of data collected and analysed. Interviews were not audio taped or transcribed verbatim resulting in fragmentation of the data and risk of loss of meaning. Possible defective memories due to the interviews taking place shortly after ICU discharge. Memories limited to ICU stay, therefore other potentially traumatic events occurring before or after were not considered.	90% (CASP)
Sukantarat et al. (2007)	UK	Quantitative To measure levels of anxiety, depression and post-traumatic stress among survivors of a critical illness and to relate these symptoms to general health parameters.	518 ICU patients invited to participate. ($n = 51$)	Questionnaires at 3 then 9 months post ICU discharge. – The EuroQol 'thermometer' and the Short Form 36 (SF-36) questionnaire. – Hospital Anxiety and Depression Scale. – Impact of Events Scale.	Strong internal correlations between: – Anxiety and depression; – Intrusion and avoidance; – Role limitation due to physical problem, social functioning, energy/vitality and pain; – Age and LOS in ICU. At 3 and 9 months post ICU discharge 24% of patients qualified as a 'case; of anxiety.' Depression and avoidance was higher on each occasion. Four of the SF-36 domains improved with time. No significant difference in physical symptom scores. Strong correlation between the physical and psychological parameters at each time point.	Small sample size. Self-reported questionnaires do not diagnose PTSD, a formal psychiatric interview is required.	92% (CASP)
Tembo et al. (2012)	Australia	Qualitative – Phenomenology To explore the experience of critically ill patients in ICU and beyond.	12 ICU patients.	In-depth face-to-face interviews were conducted at two weeks after ICU discharge and at six to eleven months later. Thematic analysis as per van Manen's six dynamic interplay activities	Overarching theme of 'being in limbo' under which three major themes of 1. Disruption 2. Imprisonment 3. Being trapped	Single centre study.	100% (CASP)

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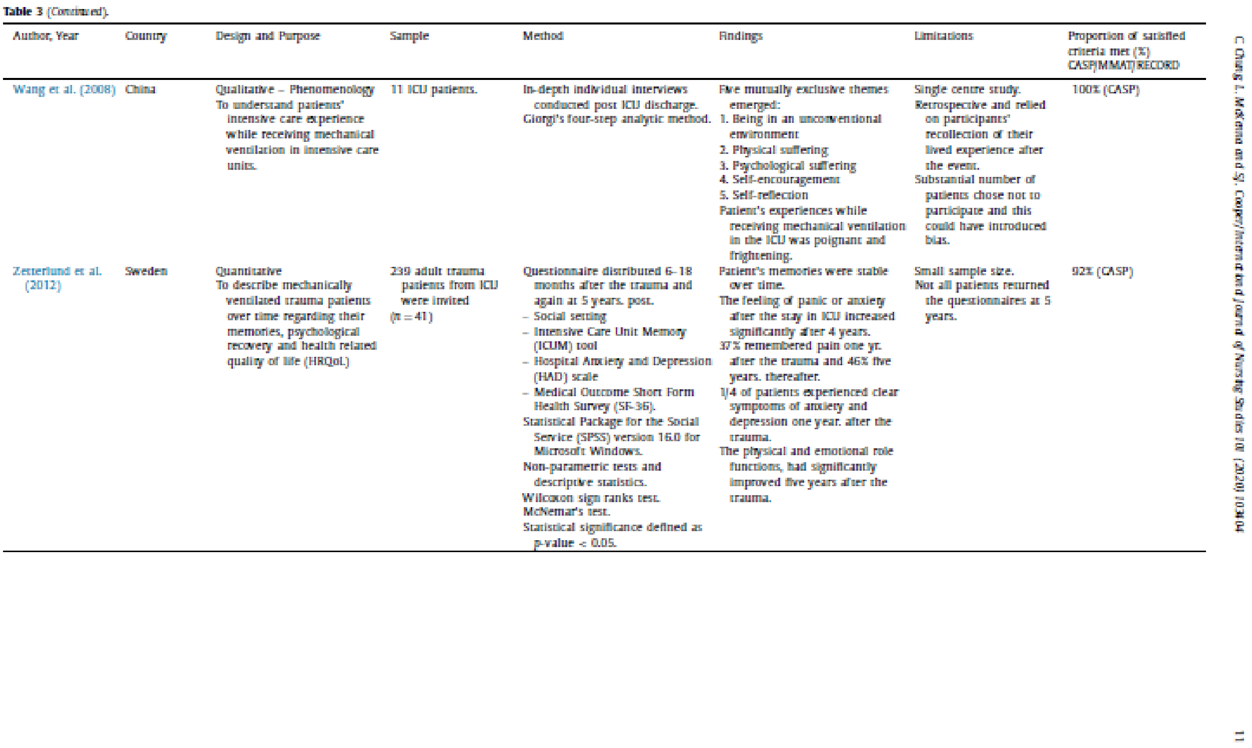


Table 3 (Continued).

Author, Year	Country	Design and Purpose	Sample	Method	Findings	Limitations	Proportion of satisfied criteria met (%) CASP|MMAT|RECORD
Wang et al. (2008)	China	Qualitative – Phenomenology To understand patients' intensive care experience while receiving mechanical ventilation in intensive care units.	11 ICU patients.	In-depth individual interviews conducted post ICU discharge. Giorgi's four-step analytic method.	Five mutually exclusive themes emerged: 1. Being in an unconventional environment 2. Physical suffering 3. Psychological suffering 4. Self-encouragement 5. Self-reflection Patient's experiences while receiving mechanical ventilation in the ICU was poignant and frightening.	Single centre study. Retrospective and relied on participants' recollection of their lived experience after the event. Substantial number of patients chose not to participate and this could have introduced bias.	100% (CASP)
Zetterlund et al. (2012)	Sweden	Quantitative To describe mechanically ventilated trauma patients over time regarding their memories, psychological recovery and health related quality of life (HRQoL)	239 adult trauma patients from ICU were invited ($n = 41$)	Questionnaire distributed 6–18 months after the trauma and again at 5 years. post. – Social setting – Intensive Care Unit Memory (ICUM) tool – Hospital Anxiety and Depression (HAD) scale – Medical Outcome Short Form Health Survey (SF-36). Statistical Package for the Social Service (SPSS) version 16.0 for Microsoft Windows. Non-parametric tests and descriptive statistics. Wilcoxon sign ranks test. McNemar's test. Statistical significance defined as p-value < 0.05.	Patient's memories were stable over time. The feeling of panic or anxiety after the stay in ICU increased significantly after 4 years. 37% remembered pain one yr. after the trauma and 46% five years. thereafter. 1/4 of patients experienced clear symptoms of anxiety and depression one year. after the trauma. The physical and emotional role functions, had significantly improved five years after the trauma.	Small sample size. Not all patients returned the questionnaires at 5 years.	92% (CASP)

Table 4
Summary of the key issues emerging from the seven themes.

Key Issues	Specific aspects	Sources	Sample quotations
Transformation of perception: memories of factual events	Inability to distinguish reality	Adamson et al. (2004); Cox et al. (2009); Dziadzko et al. (2017); Engstrom et al. (2013); Hofhui et al. (2008); Johnson et al. (2006); Kean et al. (2016); Lof et al. (2006); Olsen et al. (2017); Papathanassoglou et al. (2003); Samuelson (2011); Tembo et al. (2012); Wang et al. (2008); Zetterlund et al. (2012);	*I was in another world. I was seeing faces and I was talking to them. And there were strange things. I would have sworn that it was all true – absolutely.* (Adamson et al., 2004; p.261)
Psychological transformation: emotional distress and well-being	Emotional anguish: anger, fear, loss, frustration, hopelessness, avoidance, apprehension, powerless, loneliness/isolation, guilt, anxiety and depression	Adamson et al. (2004); Cox et al. (2009); Cypress (2011); Dziadzko et al. (2017); Kean et al. (2016); Lof et al. (2006); Papathanassoglou et al. (2003); Rosa et al. (2017); Samuelson (2011); Sukantarat et al. (2007); Wang et al. (2008); Zetterlund et al. (2012)	*I could hear them talking about me – but I was alone, like suspended in space.* (Papathanassoglou et al., 2003; p.16)
Physiological transformation: physical distress	Pain and discomfort	Adamson et al. (2004); Cypress (2011); Dziadzko et al. (2017); Karlsson et al. (2012); Lof et al. (2006); Samuelson (2011); Wang et al. (2008)	*Then it got worse and worse. I managed to get to the local health care centre although I was gasping for breath…*(Lof et al., 2006; p.157)
Facing death.	Life threatening experience	Dziadzko et al. (2017); Lof et al. (2006); Papathanassoglou et al. (2003); Samuelson (2011);	*I was sinking and I felt very peaceful – at the same time a part of me was thinking: this is death, I am dying. I was saying good-bye in my own way.* (Papathanassoglou et al., 2003; p.17)
	Inner strength and the will to live	Alpers et al. (2012); Cypress (2011); Cypress (2015); Wang et al. (2008)	*I got help…the fact that I got proper help when I was gasping for air…I survived.* (Samuelson., 2011; p.79) *What was it that gave me strength? It is, a will to live. It is my husband and my children and grandchildren.* (Alpers et al., 2012; p.154)
The severity of acute deterioration: from the perspective of the patient.	Severity of illness and knowledge of own body	Adamson et al. (2004); Guinane et al. (2018); Johnson et al. (2006); Lof et al. (2006); Mylen et al. (2016); Olsen et al. (2017); Papathanassoglou et al. (2003)	*I did not realise how critical my condition was; I have a hard time comprehending having been on a ventilator for 20 days.* (Olsen et al., 2017; p.63)
Relationship with health care professionals and the clinical environment	Healthcare professionals: support, trust, safety and expectations	Alpers et al. (2012); Engstrom et al. (2013); Guinane et al. (2018); Hofhui et al. (2008); Lof et al. (2006); Mylen et al. (2016); Olsen et al. (2017); Samuelson (2011); Wang et al. (2008); Zetterlund et al. (2012)	*The clever and competent staff…wonderful…they counterbalanced the unpleasantness…without them I'd gone crazy.* (Samuelson., 2011; p.82)
	Patient-clinician communication and information sharing	Dziadzko et al. (2017); Engstrom et al. (2013); Guinane et al. (2018); Hofhui et al. (2008); Johnson et al. (2006); Karlsson et al. (2012); Misak (2005);Olsen et al. (2017); Zetterlund et al. (2012)	*There was a nurse who held my hand, came to sit on my bed and she stayed until I felt more relaxed again. Now, I feel it helped me very much…and even now I still know who the nurse was. I was thinking then, gosh I wish the nurse who was there the other night did the same. I think I would have had a far better night.* (Hofhui et al., 2008; p.308)
	Unfamiliar environment	Dziadzko et al. (2017); Engstrom et al. (2013); Hofhui et al. (2008); Mylen et al. (2016); Samuelson (2011); Wang et al. (2008)	*It wasn't until a few days later in this room I heard that 'MET call' and thought what is that? And looked it up (on the internet) and thought "Oh that happened to me!* (Guinane et al., 2018; p.77)
	Advanced technology	Dziadzko et al. (2017); Johnson et al. (2006); Karlsson et al. (2012); Lof et al. (2006); Samuelson (2011); Wang et al. (2008)	*When they first put that respirator on me I thought I was going to die there and then…*(Johnson et al., 2006; p.556)
The value of relationships	Family support	Adamson et al. (2004); Alpers et al. (2012); Cox et al. (2009); Cypress (2011); Dziadzko et al. (2017); Mylen et al. (2016); Olsen et al. (2017); Rosa et al. (2017); Wang et al. (2008)	*…my family members gave me courage to persist…I might have given up without their backup.* (Wang et al., 2008; p.187)

seven themes: (1) transformation of perception: memories of factual events; (2) psychological transformation: emotional distress and well-being; (3) physiological transformation: physical distress; (4) facing death; (5) the severity of acute deterioration: from the perspective of the patient; (6) relationship with healthcare professionals and the clinical environment; and (7) the value of relationships: the support of family and friends. Table 4 presents a summary of the key issues emerging from the seven themes.

3.4.1. *Transformation of perception: memories of factual events*

A key and prominent theme arising from the literature reviewed was perceptual distress. Transformation of perception describes the person's inability to distinguish reality from unreal experiences such as delusions, hallucinations and dreams (Cutler et al., 2013). Some studies aimed specifically to explore this component of the person's experience (Dziadzko et al., 2017; Lof et al., 2006; Papathanassoglou and Patiraki, 2003; Samuelson, 2011;

Tembo et al., 2012; Zetterlund et al., 2012), whereas, in other studies it emerged as a meaningful theme from the person's overall experience (Adamson et al., 2004; Cox et al., 2009; Engstrom et al., 2013; Johnson et al., 2006; Kean et al., 2016; Hofhuis., 2008; Olsen., 2017; Wang et al., 2008). This could be thought of as an influential theme as the findings described throughout this article are the result of a person's experience. If memories are influenced by an altered sense of reality, they should be understood as being interpreted through a lens of altered perception (Cutler et al., 2013).

Throughout the literature, it is suggested that changes in perceptual understanding and associated altered recall are a consequence of a number of factors: environmental, metabolic, pharmacological and psychological (Cutler et al., 2013; Lof et al., 2006; Samuelson, 2011). However, whatever the precise cause, participants consistently described the phenomena as 'terrifying', 'vivid', 'distressing', 'awful', 'bizarre', 'unreal fantasies', 'overwhelming' and 'insidious' (Adamson et al., 2004; Cox et al., 2009; Dziadzko et al., 2017; Engstrom et al., 2013; Hoflus et al., 2008; Johnson et al., 2006; Kean et al., 2016; Lof et al., 2006; Samuelson, 2011; Olsen et al., 2017; Wang et al., 2008; Zutterland et al., 2012):

> *I have memories of jumbled thoughts…it was petrifying. I could hardly tell what was real and what wasn't.* (Cox et al., 2009, p. 2704)

> *It's so vivid. I mean these dreams I had that time were so bad. They were really horrific and I will never forget it because I wasn't asleep.* (Johnson et al., 2006, p. 554)

Although some studies reported that participants remembered little about their experience, those who did often found it unpleasant, with ongoing nightmares (Samuelson, 2011; Wang et al., 2008). Participants recalled fearful events that continued for several days:

> *Those terrible, terrible nightmares…oh, when you woke up, it was an overwhelming experience, so strong and frightening. I was out of my mind…I didn't dare to sleep because of them.* (Samuelson., 2011; p.81)

In contrast, three studies (Papathanassoglou and Patiraki, 2003; Olsen et al., 2017; Tembo et al., 2012) described participants' altered perceptions as a 'peaceful sensation', dreams as 'not all bad' and 'no dreams or supernatural encounters':

> *No dreams, no going to heaven that's strange, I've heard people say they know when they're unconscious, but I didn't…so having had no supernatural experience…*(Tembo et al., 2012)

3.4.2. Psychological transformation: emotional distress and well-being

Across the studies, the psychological impact of acute deterioration raises concerns for patients and their recovery. There is a growing body of evidence suggesting that patients continue to experience psychological distress such as depression, guilt, anxiety, hopelessness, fear, loneliness, isolation, despair, and irritation after their critical event and discharge from hospital (Cox et al., 2009; Dziadzko et al., 2017; Kean et al., 2016; Lof et al., 2008; Samuelson, 2011; Papathanassoglou and Patiraki, 2003; Rosa et al., 2017; Sukantarat et al., 2007):

> *I worry that maybe it happens again like before…I am nothing like before, everything is different.* (Adamson et al., 2004; p.261)

> *Why did this happen to me? What will happen to me? Will I live or die?* (Samuelson., 2011; p.79)

In addition, participants commonly described their acute situation as terrifying, threatening to their existence and shocking, chaotic and with ongoing feelings of anger (Samuelson, 2011). This is supported by Rosa et al. (2017) where a participant reported ongoing anger and frustration after the critical event:

> *I will be angry until I die, because I died in 2005. I was a healthy, active man, a little man but strong. Now, I can't even get out of bed and go; nothing, nothing, I have a shattering weakness.* (p.e1115)

However, a sense of emotional wellbeing also emerges as participants describe a sense of relief and security about their situation (Dziadzko et al., 2017; Hofhui et al., 2008; Samuelson, 2011; Sukantarat et al., 2007; Zetterlund et al., 2012), including an overall sense of relief when they regained consciousness or realised they would survive. A sense of security was also apparent when participants reported receiving professional care (Samuelson, 2011), for example, feelings of calmness, relaxation and safety knowing healthcare professionals were present and were in control (Dziadzko et al., 2017; Hofhui et al., 2008; Samuelson, 2011; Sukantarat et al., 2007; Zetterlund et al., 2012):

> *They did everything they could to help and support me. Like they were carrying me through…through all the hard and terrible ordeals. Like something warm and human in the middle of chaos.* (Samuelson., 2011; p.80)

3.4.3. Physiological transformation: physical distress

Physical distress, including pain and discomfort, was a relatively common theme to emerge from the literature (Adamson et al., 2004; Cypress, 2011 Dziadzko et al., 2017; Karlsson et al., 2012; Lof et al., 2006; Samuelson, 2011; Wang et al., 2008). In a study of severely ill ICU patients' recall of factual events and unreal experiences, conducted by Lof et al. (2006), participants recalled a sudden and dramatic deterioration of their condition, including symptoms such as difficulty in breathing, high temperature and aching throughout their body. Similarly, Samuelson's (2011) found that participants who had acutely deteriorated and required mechanical ventilation described not being able to breathe, not getting enough air, being choked due to secretions, vomiting blood or seeing their own blood floating in the bed:

> *I couldn't speak…terrible…I wanted to explain that I felt like I was dying and didn't get any air, but I couldn't.* (Samuelson., 2011; p.78)

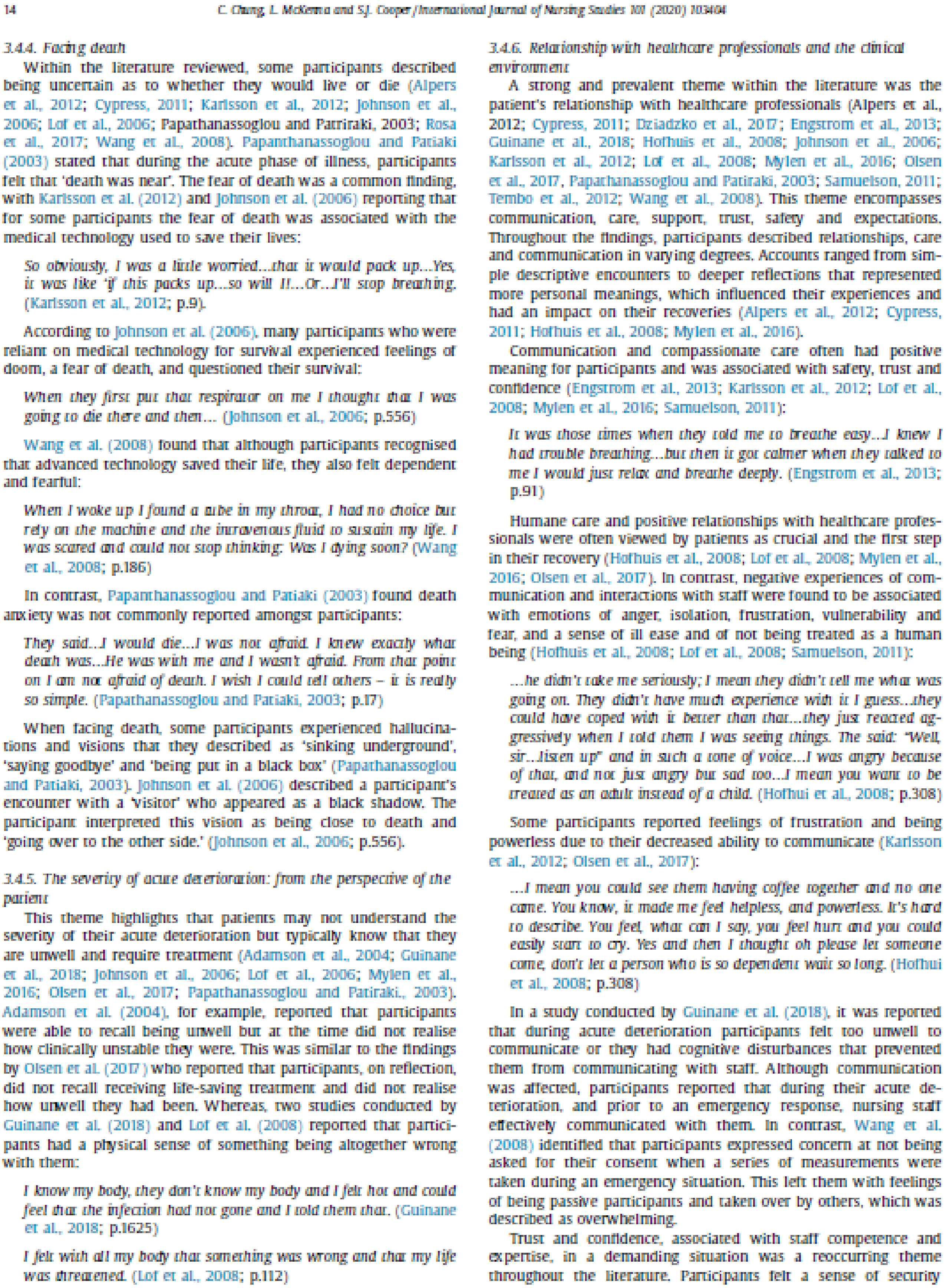
In two studies (Adamson et al., 2004; Mylen et al., 2016) participants reported vivid memories of extreme pain and discomfort. They described their experience of, and reaction to, pain as 'exploding', 'terrible', 'horrific', 'like a red-hot poker stuck in my body", 'never ending', 'I'll never forget it', 'I just screamed':

> *There was this terrible pain shot up my back and hit my head and it just kept exploding. I'll never forget it…The pain was so horrific.* (Adamson et al., 2004; p.261)

Pain was also associated with the use of advanced technology and equipment. Wang et al. (2008) found that although participants felt astounded by the machinery that helped to save their lives, they also related it to severe and unendurable pain. For example, Karlsson et al. (2012) reported participants' pain and discomfort in enduring unpleasant encounters with different clinical techniques:

> *All those tubes and lines, irritating, made me kind of crazy…and that thing in my throat, it was nasty.* (Samuelson. 2011; p.81)

In contrast, some studies reported participants' recollections of comfort and being free from pain and anxiety or feelings of discomfort but in a secure professional environment (Adamson et al., 2004).



3.4.4. Facing death

Within the literature reviewed, some participants described being uncertain as to whether they would live or die (Alpers et al., 2012; Cypress, 2011; Karlsson et al., 2012; Johnson et al., 2006; Lof et al., 2006; Papathanassoglou and Patriraki, 2003; Rosa et al., 2017; Wang et al., 2008). Papanthanassoglou and Patiaki (2003) stated that during the acute phase of illness, participants felt that 'death was near'. The fear of death was a common finding, with Karlsson et al. (2012) and Johnson et al. (2006) reporting that for some participants the fear of death was associated with the medical technology used to save their lives:

> *So obviously, I was a little worried…that it would pack up…Yes, it was like 'if this packs up…so will I!…Or…I'll stop breathing.* (Karlsson et al., 2012; p.9).

According to Johnson et al. (2006), many participants who were reliant on medical technology for survival experienced feelings of doom, a fear of death, and questioned their survival:

> *When they first put that respirator on me I thought that I was going to die there and then…* (Johnson et al., 2006; p.556)

Wang et al. (2008) found that although participants recognised that advanced technology saved their life, they also felt dependent and fearful:

> *When I woke up I found a tube in my throat, I had no choice but rely on the machine and the intravenous fluid to sustain my life. I was scared and could not stop thinking: Was I dying soon?* (Wang et al., 2008; p.186)

In contrast, Papanthanassoglou and Patiaki (2003) found death anxiety was not commonly reported amongst participants:

> *They said…I would die…I was not afraid. I knew exactly what death was…He was with me and I wasn't afraid. From that point on I am not afraid of death. I wish I could tell others – it is really so simple.* (Papathanassoglou and Patiaki, 2003; p.17)

When facing death, some participants experienced hallucinations and visions that they described as 'sinking underground', 'saying goodbye' and 'being put in a black box' (Papathanassoglou and Patiaki, 2003). Johnson et al. (2006) described a participant's encounter with a 'visitor' who appeared as a black shadow. The participant interpreted this vision as being close to death and 'going over to the other side.' (Johnson et al., 2006; p.556).

3.4.5. The severity of acute deterioration: from the perspective of the patient

This theme highlights that patients may not understand the severity of their acute deterioration but typically know that they are unwell and require treatment (Adamson et al., 2004; Guinane et al., 2018; Johnson et al., 2006; Lof et al., 2006; Mylen et al., 2016; Olsen et al., 2017; Papathanassoglou and Patiraki., 2003). Adamson et al. (2004), for example, reported that participants were able to recall being unwell but at the time did not realise how clinically unstable they were. This was similar to the findings by Olsen et al. (2017) who reported that participants, on reflection, did not recall receiving life-saving treatment and did not realise how unwell they had been. Whereas, two studies conducted by Guinane et al. (2018) and Lof et al. (2008) reported that participants had a physical sense of something being altogether wrong with them:

> *I know my body, they don't know my body and I felt hot and could feel that the infection had not gone and I told them that.* (Guinane et al., 2018; p.1625)

> *I felt with all my body that something was wrong and that my life was threatened.* (Lof et al., 2008; p.112)

3.4.6. Relationship with healthcare professionals and the clinical environment

A strong and prevalent theme within the literature was the patient's relationship with healthcare professionals (Alpers et al., 2012; Cypress, 2011; Dziadzko et al., 2017; Engstrom et al., 2013; Guinane et al., 2018; Hofhuis et al., 2008; Johnson et al., 2006; Karlsson et al., 2012; Lof et al., 2008; Mylen et al., 2016; Olsen et al., 2017, Papathanassoglou and Patiraki, 2003; Samuelson, 2011; Tembo et al., 2012; Wang et al., 2008). This theme encompasses communication, care, support, trust, safety and expectations. Throughout the findings, participants described relationships, care and communication in varying degrees. Accounts ranged from simple descriptive encounters to deeper reflections that represented more personal meanings, which influenced their experiences and had an impact on their recoveries (Alpers et al., 2012; Cypress, 2011; Hofhuis et al., 2008; Mylen et al., 2016).

Communication and compassionate care often had positive meaning for participants and was associated with safety, trust and confidence (Engstrom et al., 2013; Karlsson et al., 2012; Lof et al., 2008; Mylen et al., 2016; Samuelson, 2011):

> *It was those times when they told me to breathe easy…I knew I had trouble breathing…but then it got calmer when they talked to me I would just relax and breathe deeply.* (Engstrom et al., 2013; p.91)

Humane care and positive relationships with healthcare professionals were often viewed by patients as crucial and the first step in their recovery (Hofhuis et al., 2008; Lof et al., 2008; Mylen et al., 2016; Olsen et al., 2017). In contrast, negative experiences of communication and interactions with staff were found to be associated with emotions of anger, isolation, frustration, vulnerability and fear, and a sense of ill ease and of not being treated as a human being (Hofhuis et al., 2008; Lof et al., 2008; Samuelson, 2011):

> *…he didn't take me seriously; I mean they didn't tell me what was going on. They didn't have much experience with it I guess…they could have coped with it better than that…they just reacted aggressively when I told them I was seeing things. The said: "Well, sir…listen up" and in such a tone of voice…I was angry because of that, and not just angry but sad too…I mean you want to be treated as an adult instead of a child.* (Hofhui et al., 2008; p.308)

Some participants reported feelings of frustration and being powerless due to their decreased ability to communicate (Karlsson et al., 2012; Olsen et al., 2017):

> *…I mean you could see them having coffee together and no one came. You know, it made me feel helpless, and powerless. It's hard to describe. You feel, what can I say, you feel hurt and you could easily start to cry. Yes and then I thought oh please let someone come, don't let a person who is so dependent wait so long.* (Hofhui et al., 2008; p.308)

In a study conducted by Guinane et al. (2018), it was reported that during acute deterioration participants felt too unwell to communicate or they had cognitive disturbances that prevented them from communicating with staff. Although communication was affected, participants reported that during their acute deterioration, and prior to an emergency response, nursing staff effectively communicated with them. In contrast, Wang et al. (2008) identified that participants expressed concern at not being asked for their consent when a series of measurements were taken during an emergency situation. This left them with feelings of being passive participants and taken over by others, which was described as overwhelming.

Trust and confidence, associated with staff competence and expertise, in a demanding situation was a reoccurring theme throughout the literature. Participants felt a sense of security knowing that if they deteriorated they would be effectively cared for (Engstrom et al., 2013; Guinane et al., 2018; Mylen et al., 2016; Olsen et al., 2017). Participants felt that simply communicating a concern to the clinicians meant that they would be managed effectively and that they would comply with recommendations (Guinane et al., 2018).

Several studies described participants' experiences with the clinical environment and technology (Engstrom et al., 2013; Johnson et al., 2006; Papathanassoglou and Patiraki, 2003; Samuelson, 2011; Tembo et al., 2012; Wang et al., 2008). Participants reported feelings of discomfort, distress and isolation due to unfamiliar environments. In two ways, they recalled advanced technology used in treatment. Firstly, the inability to communicate due to restriction, such as being mechanically ventilated, and secondly, that the technology generated feelings of anger, dependency and vulnerability (Johnson et al., 2006; Samuelson, 2011; Tembo et al., 2012; Wang et al., 2008):

> *When I woke up I had the tube down my throat and had to depend on the (ventilator) and all the drips and tubes for my very life. It was terrifying at first, because you could help thinking, 'What if something goes wrong with one of these machines, and nobody knows?' After all, machinery is no infallible, is it? I tried so hard not to panic too much, but your whole life seems to lie in balance in the hands of a bit of machinery.* (Johnson et al., 2006; p.556)

3.4.7. *The value of relationships: the support of family and friends*

Ten studies discussed the importance of family and friends and how their illness affected them (Adamson et al., 2004; Alpers et al., 2012; Cox et al., 2009; Cypress, 2011; Dziadzko et al., 2017; Mylen et al., 2016; Olsen et al., 2017; Rosa et al., 2017; Wang et al., 2008). Across these, having support from family and friends was associated with feelings of safety, security and encouragement. However, they recalled being concerned about their loved ones, their health, how they would cope at home with children, and becoming a burden for them. For example, in a study conducted by Adamson et al. (2004), it was found that visiting relatives showed symptoms of anxiety and depression, which continued after their loved ones, had been discharged. During recovery, studies also reported participants' feelings of fear and anxiety of becoming unwell again and putting their loved ones through further distress (Cox et al., 2009; Loft et al., 2008):

> *When I was in hospital, my brother wasn't able to work. My mama still has to take care of me. She hasn't worked for six months. It's a big money thing. I absolutely feel like a burden on them.* (Cox et al., 2009; p.2706)

4. Discussion

This scoping review was conducted to explore literature reporting the experiences of acute deterioration, from the perspective of the patient. To our knowledge, this is the first literature review to assess the extent of evidence around this topic, published between the years 2000 and 2018. Within the literature reviewed, differences in focus, design, data collection methods and analysis were identified, which indicates a heterogeneous body of literature. However, the studies reviewed represent an expansion of knowledge across several continents with the emergence of common themes evidence of transferability and dependability (Cutler et al., 2013; Shenton, 2004).

This review confirms there has been much written about the patient's experience of critical illness while being cared for in the critical care/intensive care environment, while only one study (Guinane et al., 2018) reported on general ward patients' experiences of acute deterioration and the associated medical emergency team (MET) response. A second study conducted by Rosa et al. (2017) reported on the patient's experience of acute exacerbation of a chronic illness following hospitalisation. This review exposes a gap in current knowledge about patients' experiences of acute deterioration across different clinical environments i.e., general medical and surgical wards. Patients are in a unique position to provide insightful information to healthcare providers of problems in the care process, which could involve the care environment (Doyle et al., 2013).

The majority of literature reviewed focussed on critical care admission as a central element, with some also exploring the patient's recovery after discharge. Few studies reported on the entire illness-recovery trajectory, specifically the patient's experience of acute deterioration and initial life-saving management they received. In the current healthcare climate, there is an increasing proportion of patients with complex chronic medical conditions being cared for on general wards, increasing patient acuity and compromising their overall safety (AIHW, 2008). Additionally, patient experiences and satisfaction have become central targets internationally for quality improvements in the healthcare system (ACQSHC, 2017; Soowhan et al., 2017). For example, Glickman et al. (2010) explored patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction. The authors found that better patient experiences were associated with improved clinical outcomes and health service efficiency (Glickman et al., 2010). Despite increasing emphasis, the literature suggests that many health care organisations fall short of providing patients with optimal experiences (Rozenblum et al., 2013; Jha et al., 2008). Therefore, this review highlights that exploring general ward patients' experiences of acute deterioration has merit.

Perceptual, emotional and physical distress was found to be commonly reported in the studies included in this review. This was similar to the findings by Cutler et al. (2013) who conducted a critical review and synthesis of qualitative research on patient experiences of a critical illness. Specifically in relation to perceptual distress, the researchers suggest that memories and interpretations are influenced by an altered sense of reality and should therefore be viewed through a lens of altered perception (Cutler et al., 2013). The nature and varying degrees of distress experienced by participants was well documented and emerged as a stressor capable of affecting their psychological wellbeing and recovery. In a personal account, Misak (2005) recalls 'two sorts of awfulness' that occurred during her own acute deterioration. This included severe pain and discomfort as well as harrowing hallucinations and paranoid delusions that occurred in real time. In another personal account, Bowers (2004) recalls the emotional distress following an acute maternal deterioration event and the loss of her baby. This highlights the emotional, as well as physiological impact of acute deterioration with the potential to negatively affect a person's recovery and perceptual wellbeing. Over recent years, survival rates of critically unwell patients have improved due to advances in critical care medicine (Rawal et al., 2018). Survivors can acquire new physical, mental and cognitive impairments from ICU treatments that negatively affect the quality of life of survivors, known as 'post-intensive care syndrome' (PICS) (Needham et al., 2012). The growing body of PICS research has resulted in the development of interventions (ABCDE bundle, ICU diaries, counselling etc.) aimed at preventing or reducing the occurrence of PICS (Castro-Avila et al., 2015; Engstrom et al., 2013; Garrouste-Orgeas et al., 2012; Jensen et al., 2015; Sosnowski et al., 2018). Current literature suggests that these interventions can improve long-term functioning capacity and quality of life of ICU survivors (Rawal et al., 2018). It is particularly concerning that survivors of acute deterioration indicate they are experiencing perceptual, emotional and physical distress that may go undetected by health care providers.

From the literature reviewed, a common theme to emerge was patients recognising their own acute deterioration. Commonly, patients are astute at noticing the onset of physical symptoms but unable to interpret their clinical significance (Guinane et al., 2018). Internationally, there is a large body of evidence associated with the use of track and trigger systems by healthcare professionals to predict acute deterioration. However, recent studies suggest that although patient deterioration can often be predicted by close observation of vital signs, they are not always appropriately acted upon (Currey et al., 2018; Gill et al., 2016; Quirke et al., 2011; Strickland et al., 2019). According to Stickland et al. (2019), in an effort to reduce adverse events, Patient and Family Activated Escalation Systems (PFAES) have been introduced to enable patients and families to escalate their concerns (Dean et al., 2008; Gerdick et al., 2010; Greenhouse et al., 2006; Odell et al., 2010; Strickland et al., 2019). Strickland et al. (2019) explored patients' and families perception of a need for a patient and/or family activated escalation service. The authors reported an overwhelming support by consumers for PFAES but recognised further research is required on how the service is used and the type of calls made.

The healthcare professional-patient relationship has been described as an essential component to patient care and is based on trust and respect (Griffith, 2013). A range of issues relating to healthcare professionals and the clinical environment were identified through the reviewed studies. Studies in this review suggest that a patient's interaction with healthcare professionals can have a significant impact on their experience and recovery (Alpers et al., 2012; Cypress, 2011; Hofhuis et al., 2008; Mylen et al., 2016). Care, relationships and communication have been raised as important aspects of personal meaning for participants and their security and safety, for example Hofhuis et al. (2008), who explored the experiences of critical illness in the Intensive Care Unit (ICU). The quality of the nurse-patient relationship (NPR), for example, has been found to influence a patient's experiences of and benefits from, treatment and care (Strandas and Bondas, 2017). Research suggests that the NPR is one of the most important aspects for successful treatments (Molin et al., 2016; Peplau, 2004). While relationships with healthcare professionals and the clinical environment was a meaningful theme to emerge from the participants' overall experiences in this review, no studies specifically explored this component, suggesting additional research is required to inform education and training to support patient care.

Facing death or death anxiety was a common theme to emerge from the literature reviewed. The term 'death anxiety' refers to the apprehension generated by death awareness (Abdel-Khalek, 2005). Feelings of prolonged fear, anxiety, hopelessness and terror have been well acknowledged in the literature reviewed. Previous studies have shown that for medically unwell patients, facing death has been characterized by feelings of hopelessness, the loss of meaning, and the sense of failure (Clarke and Kissane, 2002; Kissane, 2014; Robinson et al., 2015). Ferreira et al. (2014) explored the relationship of death with the physical recovery of patients in ICU, finding death was feared by participants and had an impact on their recovery. It would appear that facing death is a major aspect of acute deterioration, effecting a survivor's life in different ways. In addition, Cutler et al. (2013) reported that facing death whether it be personal, actual, imagined or feared contributes to a transformation in the meaning of life. Therefore, it is essential that health care professionals consider death anxiety when caring for patients experiencing acute deterioration and provide necessary therapeutic support.

4.1. Strengths and limitations

This scoping review has several strengths worth noting. The recognition and management of acute deterioration is a priority world-wide and this review focuses on the most recent research. To increase the probability of the uptake of the scoping review findings into policy and practice, the quality of the included studies were independently assessed by two researchers. All authors carried out screening of titles and abstracts, and a random selection of full-text articles. After reaching agreement, the first author continued the title-abstracts screening process. All authors validated emerging and final themes. Some limitations need to be acknowledged. Not included were personal narratives, government documents, review books, or policy papers that reported on patients' experiences of acute deterioration. While the review was broad, some relevant studies may have been omitted. In addition, the review only included literature published in English between the years 2000 and 2018 therefore, relevant literature may have been omitted where published in other languages or outside the year range. Despite these limitations, the review does provide important understandings of patients' experiences of acute deterioration.

5. Conclusion

This scoping review provides a comprehensive summary of primary research findings concerning patients' experiences of acute deterioration. An integrated understanding of patient needs during acute deterioration may support tailored and feasible interventions in everyday nursing practice to improve quality of care. This review has highlighted the limited research conducted in the area of patients' experiences of acute deterioration, including the medical emergency management they receive. This suggests additional research is required to inform education, practice and policy to support patient care.

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Conflict of interest

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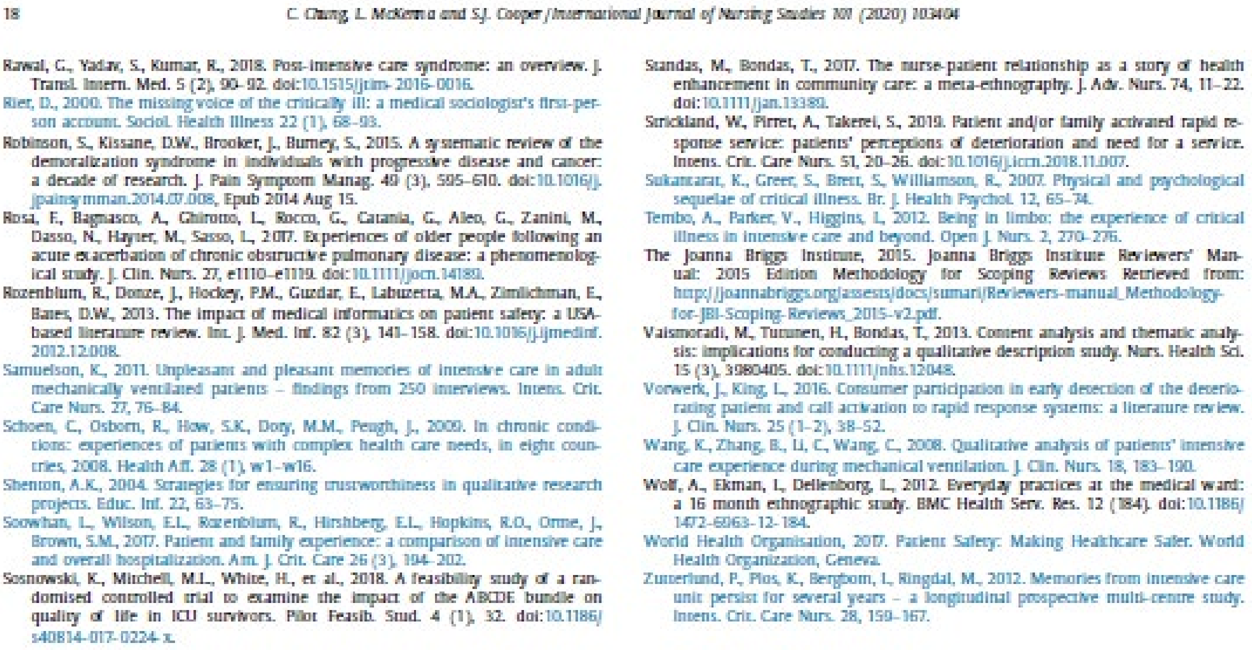

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2.3 Summary of Chapter Two

This chapter offered a preliminary review of the current literature relevant to the research context. The scoping review explored the current literature on patients' experiences of acute deterioration and identified gaps in knowledge, which the current study aimed to explore. This paper highlights what is already known on the topic of interest and provides the reader with the necessary background and understanding. This scoping review has highlighted that patients experience emotional, physical, and perceptual distress during acute deterioration. In the following chapter, a discussion about the theoretical underpinnings employed to explore the study aim and question is provided.

CHAPTER THREE

Methodology

Chapter Three: Methodology

"We can share the journey, but the adventure is yours" (Charmaz, 2014)

3.1 Introduction

When conducting and reporting research, a major challenge for researchers is striving for the highest possible quality (Cope, 2014). The credibility of any research is reliant on the truth of the data or the participants views and how they are interpreted and represented by the researcher (Polit & Beck, 2012; Ralph, 2013). When conducting research, it is crucial that an in-depth understanding of the research methodology employed is discussed (Ralph et al., 2015). In this study, the aim was to generate a substantive theory to understand patients' experiences of acute deterioration where a (MET) review occurred. It is anticipated that understanding this interpretation will contribute to the body of knowledge and inform clinical practice and education. To achieve the study aim, constructivist grounded theory (CGT) methodology was employed.

The purpose of Chapter Three is to provide a detailed insight into the study methodology. The chapter begins with a general discussion about the philosophical underpinnings of qualitative research and progresses through to the philosophy of grounded theory including the fundamental tenets of data collection, data analysis and theory integration. A detailed insight is provided as well as an argument for the chosen methodology of CGT.

3.2 Qualitative Research Methods: Philosophical and Theoretical Underpinnings

Qualitative researchers are philosophers in that "universal sense in which all human beings…are guided by highly abstract principles" (Bateson, 1972, p. 320). According to Denzin and Lincoln (1994), "qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter" (p. 2). Creswell (1998) defines qualitative research as "… an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting" (p. 5). Simply stated, to comprehend the meaning of the participant's existence, the qualitative researcher must get as close as possible to that life.

Qualitative research was first undertaken by sociologists and anthropologists in the early twentieth century as a structured method of inquiry (Denzin & Lincoln, 2011). Since this time, contemporary qualitative research has evolved to include a range of disciplines with researchers adopting different perspectives to guide their research. According to Savin-Baden and Howell Major (2013), without philosophical underpinnings, method can become a meaningless process and therefore is necessary to make better research choices and outcomes. Guba and Lincoln (1994), in an attempt to classify contemporary social research studies, identified critical theory and constructivism as the two main paradigms adopted by qualitative researchers. However, Savin-Baden and Howell Major (2013), disagree suggesting there are several different philosophies that qualitative researchers work within: critical social theory (power relationships), pragmatism (observation of natural behaviour in natural context), phenomenology (human experience), post-modernism/structuralism (text and subtext and their deeper meaning), social constructionism (interpretation of subject meaning and shared knowledge developed through interaction) and constructivism (individuals make and socially construct theory own meaning).

3.2.1 Paradigms of Inquiry Within Qualitative Research

Paradigms are defined by Ellen (1984) as "models or frameworks that are derived from a worldview or belief system about the nature of knowledge and existence" (p. 9). As explained by Guba (1990a), a paradigm or interpretative framework encompasses the researcher's ontological, epistemological and methodological principals. According to Holloway and Wheeler (2010), research is not confined to data collection, analysis and sampling but based on a set of valued beliefs and assumptions about the world, the nature of reality and how reality can be known. Qualitative inquiry relies on these assumptions so the researcher can engage in the participant's world to gain an understanding of their interpretation of reality. The researcher's assumptions about the nature of social reality (ontological), the nature of the relationship between the knower and what can be known (epistemological) and the how we know the world or gain knowledge of it (methodological) are considered important principles which are embedded within the interpretive and constructivist paradigm of qualitative research (Annells, 1996; Denzin & Lincoln, 2011; Guba & Lincoln, 1994; 2005).

3.2.2 Constructivism Paradigm

According to Guba and Lincoln (1989), constructivism is a research paradigm that rejects the existence of an objective reality, "asserting instead that realities are social construction of the mind, and that there exist as many such constructions as there are individuals (although clearly many constructions will be shared)" (p. 43). Mills et al. (2006) state that to deny the existence of an object reality places individuals in a relativist ontological position. Relativists claim that concepts such as reality, truth, rationality, right, good or norms must be understood as relative to the specific conceptual scheme, paradigm, theoretical framework, society, culture, or form of life (Bernstien, 1983; Charmaz, 2014; Mills et al., 2006). Simply meaning that relativists believe the world consists of multiple individual realities that are influenced by the context they occur.

Constructivism, from an epistemological perspective, emphasises the subjective interrelationship between the researcher and participants, and the co-construction of meaning (Hayes & Oppenheim, 1997; Pidgeon & Henwood, 1997). Researchers are not objective observers, they are part of the research journey and their values must be recognised by themselves and by their readers as an inevitable part of the outcome (Appleton, 1997; Charmaz, 2014; de Laine, 1997; Guba & Lincoln, 1989; Mills et al., 2006; Stratton, 1997).

In undertaking research, constructivists aim to understand the way meanings are constructed and to comprehend how this meaning is presented and used through language and action. Constructivists use a range of methods to seek and explore an individual's reconstruction of their realities (Savin-Baden & Howell Major, 2013). Creswell (2003) explains that throughout the research process, constructivists do not begin with a theory but instead "generate or inductively develop a theory or pattern of meanings" (p. 9).

3.3 Symbolic Interactionism: Philosophical Underpinning of Grounded Theory

Symbolic interactionism is the major theoretical perspective associated with grounded theory and views human actions as "constructing self, situation, and society" (Charmaz, 2014, p. 262). Symbolic interactionism builds on the assumptions that a) people strive and act toward what represents meaning to them, b) meaning arises out of social interaction, c) meanings are modified through interpretive process (Handberg et al., 2014; Meltzer et al., 1975). Because of this, Symbolic interactionism is considered a powerful framework to guide research that aims to understand human health behaviour within a social context (Fiori et al., 2017; Handberg et al., 2014). In keeping with the constructivist paradigm, symbolic interactionism is the underlying theoretical perspective of this study. The foundations of symbolic interactionism were formed predominantly by philosopher George Herbert Mead from the University of Chicago in the early twentieth century. In Mead's (1934) view, meanings emerge from experienced interactions, formed from language, and change when something stimulates review (Charmaz, 2014). Mead's theory of the development of a social self has taken a focal place in sociological social philosophy (Mead, 1934).

3.4 The Emergence of Grounded Theory Methodology

The emergence of grounded theory methodology (GTM) was a result of the tension between qualitative and quantitative research in sociology in the early 1960s. GTM emerged from the successful collaboration between sociologists Barney Glaser and Anslem Strauss at the University of

California, San Francisco in the 1960s and early 1970s (Charmaz, 2014). Under the supervision of philosopher Herbert Blumer, Strauss trained in symbolic interactions pragmatism while Glaser trained in quantitative sociology (Charmaz, 2014; Glaser & Strauss, 1967). Grounded theory emerged as a methodology that “combines the depth and richness of qualitative interpretive traditions with the logic, rigor and systematic analysis inherent in quantitative survey research” (Walker & Myrick, 2006, p. 548). Glaser and Strauss’ successful collaboration came while studying death and dying in a variety of hospital settings in the United States (Charmaz, 2014; Glaser & Strauss, 1965, 1968; Strauss & Glaser, 1970). As a result of this study, Glaser and Strauss developed systematic methodological strategies that researchers could adopt when studying other topics (Birks & Mills, 2015). In their 1967 publication, *The Discovery of Grounded Theory; Strategies for Qualitative Research,* Glaser and Strauss refocused qualitative inquiry on methods of analysis (Charmaz, 2014). The individual backgrounds of Glaser and Strauss has influenced the development of grounded theory. Glaser’s positivist influence is evident through the structure and process of grounded theory while Strauss’ perspective of symbolic interactionist provides the philosophical direction to the methodology (Cooney, 2010; Melia, 1996). Since its inception, grounded theory has evolved significantly and undergone both clarification and change (Charmaz, 2000; Glaser 1978; 1999; Strauss, 1987; Strauss and Corbin, 1990).

Prior to the development of grounded theory, the long tradition of qualitative research in sociology was losing ground as sophisticated quantitative methods were developed for testing and reproducing facts (Charmaz, 2014). According to Platt (1996), some sociologists quantified measures to persuade outside audiences, not because they believed quantification was necessary. Glaser and Strauss (1967) suggested that all forms of data, qualitative and quantitative was “useful for both verification and generation of theory” (p. 18). They proclaimed a revolutionary message, that systematic qualitative analysis has its own logic and could generate theory (Lee, 2006).

Grounded theory is described as a qualitative approach that aims to develop theory that is grounded in systematically collected and analysed data (Ramalho et al., 2015). Glaser (1992) defines grounded theory as “a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area” (p. 16). While researchers accept the definition, the approach and rigour in data collection, handling and analysis differs between approaches (Evans, 2013).

Grounded theory methods enable the researcher to unravel complexities of qualitative analysis and to understand moments of a person’s life (Atkinson et al., 2003). The evolution of GTM is the result of an person’s ontological and epistemological interpretations applied in the context of research (Ralph et al, 2014). From Glaser and Strauss's (1967) post-positivism to the symbolic interactionism and pragmatism of Strauss and Corbin (1990) through to the constructivism of Charmaz (2000) (Ralph et al., 2015), grounded theory is unique as "grounded theorists offer new ontological and epistemological perspectives at specific moments in time" (Ralph et al., 2015, p. 1), although differing perspectives have caused disagreements and confusion amongst grounded theorists relating to different interpretations of grounded theory. Emergent interpretations in grounded theory reflect the philosophical position of the researcher, emphasising the need for ontological and epistemological awareness (Ralph, 2013).

Originally, grounded theory was conceptualised with the aim of generating a novel theory by introducing a methodology powerful enough to endure the research process from the systematic collection of data, through to the development of a multi-dimensional conceptual theory (Handberg et al., 2014; Glaser, 1999; Glaser & Strauss, 1965; Harry et al., 2005; Lee, 2006; Ralph, 2013; Strauss, 1987; Strauss & Corbin, 1997). Commonly, grounded theory is recognised and utilised as a purely qualitative research method, but its original intention was to be a broad research method relevant in both qualitative and quantitative data systems (Handberg et al., 2014; Glaser, 1999; Glaser & Strauss, 1965; Miller & Fredericks, 1999). Since its inception, GTM has been marked by differing opinions and divergences in genres, philosophies, paradigms, methods and approaches (Ralph et al., 2014).

3.5 Why Grounded Theory Methodology

Grounded theory is a method of social scientific theory construction. Across disciplines and professions, grounded theory is adopted by researchers more frequently than any other methods for analysing qualitative data (Bryant & Charmaz, 2007; 2019; Morse, 2009; Yamazaki et al., 2009). As a methodology, it reflects a discipline or branch of knowledge, and as a method it offers systematic but flexible analytical steps that assist researchers to focus their data collection and to build middle-range theories (Charmaz, 2014; Glaser & Strauss, 1967). It is described as an iterative, comparative, interactive, and abductive method (Charmaz, 2006, 2007, 2008e; Charmaz & Henwood, 2008; Bryant & Charmaz, 2007). Grounded theory is a powerful method as it encourages the researcher to ask analytical questions during each step in the iterative process, raising the abstract level of the analysis (Charmaz, 2011, 2014). By using comparative methods throughout the analytical and writing process it "sharpens a researcher's emerging analysis" (Charmaz, 2011, p.361). Because of the unique nature of grounded theory methods, it is best suited when:

- The research intends to generate a theory with explanatory power (Birks & Mills, 2015; Charmaz, 2014).

- Understanding a phenomenon when little is known about the area of study (Birks & Mills, 2015; Corbin & Strauss, 2008; Creswell, 2008).
- The research is aiming to construct theory about a problem of importance which involves actions and interactions between people (Creswell, 2009; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998).
- Relationships between concepts are not identified or poorly understood (Bryant & Charmaz, 2007).

Grounded theory is a popular approach to qualitative research as it seeks to explain a phenomenon. Since its inception it has been widely used throughout many disciplines such as nursing, education, medicine, public health, management and business (Bryant & Charmaz, 2010). The key strengths and features of grounded theory research are 1) the constant comparison of data with emerging categories and, 2) theoretical sampling of different groups to develop the properties of developing categories or theory (Charmaz, 2014; Corbin & Strauss, 2008; Creswell, 2009). The goal of grounded theory is to generate a theory that explains how an aspect of the social world works (Ke & Wenglensky, 2010). Therefore, this methodology was well suited to address the aims of this research, which was to explain and understand social processes, constructed in the experience of acute deterioration and MET encounter.

3.6 The Differences Between the Grounded Theory Approaches

Glaser and Strauss (1967) encouraged methodological debate and inspired generations of qualitative researchers from their book titled 'The Discovery of Grounded Theory.' In their book Glaser and Strauss proclaimed a revolutionary message, "that systematic qualitative analysis had its own logic and could generate theory" (Glaser & Strauss, 1967, p. 48). Charmaz (2014) suggests that Glaser and Strauss provided a powerful argument that legitimised qualitative research as a credible and rigorous methodological approach, instead of as a precursor for developing quantitative instruments.

Since Glaser and Strauss' original statement in 1967 (Glaser & Strauss) and 1978 (Glaser), they have taken grounded theory in different directions. Glaser has maintained a positivist approach that emphasises the objectivity of the researcher (Lee, 2006). According to Charmaz (2014), Glaser defines grounded theory as a method of discovery, treats categories as emergent from the data, relies on a direct empiricism, develops a concept-indicator approach, considers concepts to be variable and emphasises analysing a basic social process. Whereas Strauss (1987) in collaboration with Juliet M. Corbin (Strauss & Corbin, 1990, 1998) further moved grounded theory toward seeing it as a method of verification. Strauss and Corbin's version of grounded theory emphasised an evolved systematic approach which is viewed more constructivist or interpretive (Charmaz, 1995; Gibbs, 2002; Lee, 2006; Strauss & Corbin, 1990). Glaser (1992) argues that Strauss and Corbin's procedural approach to grounded theory forces data and analysis into preconceived categories, ignores emergence, and results in 'full conceptual description', not grounded theory (Charmaz, 2014). Glaser insists that Strauss and Corbin's approach to grounded theory contradicts it's fundamental principles (Holton, 2018).

Constructivist grounded theory (CGT)emerged in the 1990s by Professor Kathy Charmaz, a sociologist who grew dissatisfied with social constructionist approaches to research within her discipline (Stelmaszewska, 2009). A student of Glaser and Strauss, Charmaz (2000) recognised that researchers treated their analysis as "accurate renderings of the world they studied rather than as a construction, they did not take into account their processes of construction of the research and the structural and situational encroachment upon it" (p. 14). From this discovery, CGT emerged to acknowledge the subjectivity as well as the researcher's involvement in the construction and interpretation of data (Birks & Mills, 2015).

The constructivist approach to grounded theory treats research as a construction but acknowledges that it occurs under specific conditions (Charmaz, 2014). As discussed by Birks and Mills (2015), CGT highlights flexibility of methods and resists mechanical application, an approach encouraged by Glaser and Strauss (1967) in their original statement. CGT accepts that social reality is multiple and constructed (Birks & Mills, 2015) therefore, the researcher's "position, privileges, perspective and interactions must be taken into account as an inherent part of the research reality" (Charmaz, 2014, p. 13). Clarke (2012, p. 13) supports this by stating that the "research reality arises within a situation and includes what researchers and participants bring to it and do with it." Observing research as constructed instead of discovered, fosters researchers' reflexivity about their actions and decision (Charmaz, 2011).

3.7 The Fundamental Tenets of Grounded Theory Methodology

3.7.1 Data Collection in Grounded Theory Methodology

Fundamental and unique to grounded theory research design is the process of concurrent data collection and analysis. Charmaz (2006, 2014) emphasises the important of gathering rich data as it reveals participants' views, feelings, intentions, and actions as well as the context and structures of their lives. Rich data is detailed, focused and full which will generate strong grounded theories. Throughout the research process rich data can comes from multiple sources such as interviews, observations, field notes, documents and questionnaires (Birks & Mills., 2011; Charmaz, 2006, 2014).

Glaser and Strauss (1967) do not direct the researcher towards a preferred data collection method. Glaser (2002) states that 'all is data', that everything the researcher learns about the research topic or in the research setting serves as data. Corbin and Strauss (1990) emphasise that a major source of effectiveness in grounded theory is the process of data collection and analysis as it captures all potentially relevant aspects as they are perceived. They place high importance on provisional 'concepts' that "earn their way into the theory by repeatedly being present in each interview, document, observation, in one form or another, or by being significantly absent" (Corbin & Strauss, 1987, p. 420). Charmaz (2012, 2014) agrees with Glaser's notion that 'all is data' but identifies interviewing as the most frequent source of data in grounded theory. Charmaz (2014) highlights that data varies in quality, relevance to the emerging theory and usefulness for the interpretation. Charmaz (2014) also notes that researchers differ in the ability to distinguish useful data as well as their attention to detail when recording them. Charmaz (2014, p. 29) outlines:

> "People construct data – whether it be research generating first-hand data through interviews or field notes or gathering documents and information from other sources such as historical texts, government records, or organisational information complied for private discussion or public dissemination. Whatever stands as data flows from some purpose to realise a particular objective. In turn, purposes and objectives arise under particular historical, social and situational conditions."

In this research study, the chosen data collection method, to address the aims of the study and to keep with the unpinning tenets of grounded theory, in-depth individual interviews were conducted using a semi-structured interview guide.

3.7.1.1 Theoretical Sampling

Theoretical sampling is a unique and essential method of grounded theory, it is responsible for the development and refinement of a theory that is 'grounded' in the data (Breckenridge & Jones, 2009). As preliminary data is collected, theoretical sampling provides a direction for the next stage of data collection in a process of concurrent analysis that continues until categories are fully developed or 'saturated' (Birks & Mills, 2011). Glaser and Strauss (1967) originally defined theoretical sampling as "the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them in order to develop his theory as it emerges" (p. 45). According to Birks and Mills (2015), this definition remains accurate for the contemporary grounded theorist, whereas Charmaz (2006) suggests "theoretical sampling is interpreted differently by different researchers" (Birks & Mills, 2015, p. 68).

The process of theoretical sampling begins with the identification of key concepts that will be studied, to give a foundation to the research. Theoretical sampling, coupled with theoretical sensitivity, will ensure that the raw data is reflected, or grounded, in the final theory produced (Mills et al., 2014). Once tentative theoretical categories are developed from the data, theoretical sampling guides the researcher to seek events, people or information to define and illuminate the properties, relevance and boundaries of the category or set of categories (Bryant & Charmaz, 2019; Charmaz, 2014). Strauss and Corbin (1998) suggest that theoretical sampling will direct the researcher to return to a data source a number of times to gather more information or seek clarification of data that have already been collected. This process continues until all possible categories are identified and are considered to be saturated (Charmaz, 2014; Lawrence & Tar, 2013; McCann & Clark, 2003a). Saturation of categories, as defined by Glaser and Strauss (1967), is a "criterion for judging when to stop sampling the different groups pertinent to a category" (p. 61). Starks and Trinidad (2007, p. 1375) suggest theoretical saturation is achieved "when the complete range of constructs that make up the theory are fully represented by the data." Corbin and Strauss (2008) suggest that in some instances of research it is necessary to accept what data are available, but the researcher must make every effort to apply the principles of theoretical sampling and follow leads generated during analysis. If this occurs, the researcher must acknowledge the limitations and the impact it may have on the final theory.

3.7.1.2 Theoretical Sensitivity

A key concept of grounded theory is the researcher's acquisition of theoretical sensitivity (Hoare et al., 2012). Glaser (1978) described theoretical sensitivity as "an individual's ability to render theoretically their discovered substantive grounded theory" (p. 1). Theoretical sensitivity is the ability to develop insight, understanding and give meaning to the data, and also to detach the relevant from irrelevant (Strauss & Corbin, 1990, 1998). Charmaz (2006) and Hoare et al., (2012) suggest that sensitivity is reached by stopping and thinking again, by reflecting on and comparing multiple vantage points, as well as building on ideas and following leads. It is the responsibility of the researcher to have theoretical insight related to the data and their relationships between concepts and personal experiences. Hoare et al., (2012) suggest that to increase theoretical sensitivity, a researcher can use analytical tools such as personal experience, questions, initial coding, memos, theoretical sampling, and professional experience.

3.7.2 Data Analysis in Grounded Theory Methodology

An essential method that differentiates grounded theory from other qualitative research designs is concurrent data collection or generation and analysis using codes and categories (Birks & Mills, 2015). In grounded theory, the well-defined process of data analysis begins with basic description then conceptual ordering before moving onto theorising (Patton, 2002; Walker & Myrick, 2006). Data analysis is accomplished by a coding process that is the “fundamental analytic process used by the researcher” (Corbin & Strauss, 1990, p. 12), although the way data is analysed in grounded theory research is dependent on the approach adopted by the researcher. Glaser (1978) divides the coding process into two procedures: substantive and theoretical coding. Substantive coding consists of two sub-phases, open and selective coding that aims to develop categories and their properties. Theoretical coding occurs at a conceptual level, merging substantive codes together into a theory (Walker & Myrick, 2006), whereas Strauss and Corbin (1990, 1998) divide the process into three phases: open, axial and selective coding. They insisted on using constant comparative methods and questions within these phases with each having specific procedures aimed at achieving distinct purposes. Walker and Myrick (2006) suggest that initially Strauss and Corbin’s coding process appears simple; however, when moving deeper into the method, the procedures the researcher must use become increasingly more complex. Both Glaser’s and Strauss’ versions of grounded theory adhere to the same basic research process, but the difference lies in how the processes and use of language is carried out.

For this research, data were analysed using a CGT approach. The aim of a constructivist approach is to develop theoretical interpretation of the data while allowing flexibility in data analysis as the steps are interwoven and not discrete when applied by the researcher (Charmaz, 2014). Charmaz (2000, 2006, 2014) focusses on three coding procedures of initial, focused, and theoretical coding. Charmaz (2014) further incorporates four different phases in developing concepts and theoretical framework including: (1) creating and refining the research and data collection procedures, (2) raising terms to concepts, (3) asking conceptual questions, and (4) clarification of concepts through writing and re-writing.

3.7.2.1 Coding and Categorising

Coding in grounded theory is the process of analysing the data which involves the researcher as an active participant in the process (Walker & Myrick, 2006). Glaser (1978) describes codes as “the essential relationship between data and theory” and coding as a process that, “gets the analyst off the empirical level by fracturing the data, then conceptually grouping it into codes that then become the theory that explains what is happening in the data” (p. 55). While Charmaz (2000, 2006,

2014) writes, coding is the first step in moving beyond concrete statements to interpret them analytically, it is an essential link between gathering data and the emergent theory (Charmaz, 2000, 2006, 2014). Simply put, a code sets up a relationship with the data and with the participant while coding names the sections of data with a label that simultaneously categorises, summarises and accounts for each piece of data (Charmaz, 2014; Star, 2007). Coding moves the researcher beyond concrete statements in the data to make analytical sense of stories, statements, and observations. There are three main phases of coding in CGT methodology: (1) initial coding involves engaging with and defining the data. It forms the links between collecting data and developing an emergent theory, (2) focused coding is sequential to initial coding where the most frequent and significant codes are used to sift through and analyse large amounts of data. Codes demonstrating analytic strength are raised to tentative categories to be developed, and (3) Advanced level coding in CGT is theoretical coding (Charmaz, 2014). Theoretical coding follows the codes selected during focused coding and provides a framework for enhancing the explanatory power of a grounded theory (Birks & Mills, 2015; Charmaz, 2014). Charmaz (2014) advocates four phases in developing concepts in CGT methodology: (1) creating and refining the research and data collection procedures, (2) raising terms to concepts, (3) asking conceptual questions, and (4) clarification of concepts through writing and re-writing (Charmaz, 2014). However, the above phases are interwoven and not discrete when applied by the researcher (Charmaz, 2014). Grounded theory researchers interact with the data many times over to understand participants' views from their perspective (Birks & Mills, 2015).

Initial Coding

Initial coding, referred to by Glaser (1978) and Strauss and Corbin (1990) as 'open coding' and 'initial coding' by Charmaz (2014), is the first important step which moves the researcher towards later decisions about defining core conceptual categories. Birks and Mills (2015) suggest that initial coding in the first instance is a rigorous approach and encourages the researcher to examine data in fine detail while concurrently asking questions of the data. Throughout initial coding, the researcher stays close to the data and attempts to see actions in each segment of the data instead of applying pre-existing categories (Charmaz, 2014). Glaser (1978, 1992) and Charmaz (2006; 2014) agree that while conducting initial coding the researcher should not have any preconceived ideas and keep it open-ended, although Charmaz (2014) also acknowledges that the researcher holds prior ideas and skills. Glaser (1978) believes that by "running the data open" (p. 56) the analysis "carries with it verification, correction and saturation" (p.60). Although similar to Glaser (1978), Strauss and Corbin (1990) define 'open coding' as the "analytical process through which concepts are identified and their properties and dimensions are discovered in the data" (p.101). The difference is the reference to 'dimensions', as Strauss and Corbin believe that dimensionalising a category's properties is a core task (Walker & Myrick, 2006). Glaser (1992) has criticised this approach as he believes they are jumping ahead in the analysis process by automatically developing the dimensions of a property and argues it is a form of forced coding (Walker & Myrick, 2006).

Initial coding is a reflexive activity where the researcher constantly questions themselves about early analytical decisions and the coding process which will assist them to avoid forcing theoretical codes (Birks & Mills, 2015; Glaser, 1978; Strauss & Corbin, 1990). Saldana (2015) agrees and states that initial coding provides an opportunity for the researcher to reflect intensively on the contents and degrees of the data and to begin taking ownership of them. During this process, the researcher's ideas, insights, thoughts and feelings about the data and its relationship with the emergent theory are also documented in the form of memos (Schreiber, 2001). During initial coding, Glaser and Strauss (1967), Glaser (1978, p.57) and Charmaz (2014) advocate the following questions to be asked:

1. "What is this data a study of?" (Glaser, 1978, p. 57; Glaser & Strauss, 1967)
2. "What do the data suggest? Pronounce? Leave unsaid?" (Charmaz, 2014, p. 116)
3. "From whose point of view?" (Charmaz, 2014, p. 116)
4. What theoretical category does this specific datum indicate? (Glaser, 1978)

Initial coding produces codes that are provisional, comparative, and grounded in the data (Charmaz, 2014). Many grounded theorists begin initial coding by using line-by-line coding. Line-by-line coding is a "heuristic device which will bring the researcher into the data, interact with it, and study each fragment of it" (Charmaz, 2014, pg. 121). Line-by-line coding helps to define implicit meanings and action and give direction to explore, making comparisons between data, and suggested emergent links between processes in the data to pursue and check (Charmaz, 2014). This type of coding is also a thorough way for the researcher to refrain from citing their own intentions, fears, or unresolved personal issues to participants and collected data. Other types of coding processes used in the initial coding analysis to generate a range of ideas and interpretation on which theory is constructed are word-by-word, segment by segment and incident by incident coding. Additionally, initial coding also guides the researcher if there are gaps in the data (Charmaz, 2006).

Focused Coding

In the second level of the coding process, Strauss and Corbin (1990) use a three-phased method known as axial coding. According to Strauss and Corbin (1990), the purpose of axial coding is to put the fractured data back together in new ways "by making connections between a category and its subcategory" (p. 97). This connection is achieved by the coding paradigm that focuses on the situations or conditions in which the phenomenon occurs; the interactions or actions of the people in response to what is happening in the situation; and the results or consequences of the action taken or inaction (Strauss & Corbin, 1998; Walker & Myrick, 2006). Charmaz (2014) notes that axial coding assists to clarify and to extend the analytic power of the emerging ideas but casts a technological overlay on the data and final analysis. Robrecht (1995) suggests that although axial coding can make grounded theory cumbersome, the process ensures a complete grasp of the studied phenomenon. In comparison, Dey (1999) suggests Strauss and Corbin's coding paradigm makes good heuristic sense because it has an emphasis on context, conditions, and consequences. Walker and Myrick (2014) agree by stating "Strauss and Corbin are much clearer on how to reconnect or integrate the categories and subcategories" (p. 553), but they almost impose, force, or even position the data. Glaser (1978, 1992) does not support the use of axial coding and instead uses selective coding (walker & Myrick, 2014). According to Glaser (1992) selective coding is the transformation from 'running the data' open to delimiting the coding process around a core category. In terms of methodological differences, Walker and Myrick (2006) suggest the process of axial coding is very different to Glaser's method and therefore direct comparison cannot occur. Although direct comparison cannot be made, Walker and Myrick (2006) acknowledge that both coding processes have an element of selectivity, Strauss and Corbin select categories to examine, using the coding paradigm whereas Glaser selectively codes around a core category (Walker & Myrick, 2006).

In CGT, the second level of the coding process is focused coding. According to Charmaz (2000, 2006, 2014), focused coding is a significant step in organising how the researcher treats the data and manages the emerging analysis. Focused coding uses the most significant and/or frequent earlier codes to sift through and analyse large amounts of data (Charmaz, 2014). It requires the researcher to make decisions about which initial codes make the most analytic sense to categories your data incisively and completely (Charmaz, 2014). Focused codes will "advance the theoretical direction of the work by synthesising, analysing and conceptualising larger segments of the data" (Charmaz, 2014, p. 138). Charmaz (2014, p. 141) suggests the following to assist the researcher decide which codes serve best as focused codes:

1. "What do you find when you compare your initial codes with data?
2. In which ways might your initial codes reveal patterns?
3. Which of these codes best account for the data?
4. Have you raised these codes to focused codes?
5. What do your comparisons between codes indicate?

6. Do your focused codes reveal gaps in the data?”

This process of initial line-by-line and focused coding enables the researcher to reach preliminary, tentative categories for rendering the data analytically (Birks & Mills, 2015). The researcher begins focused coding when similarities in concepts are identified in the initial coding. By doing this, the initial codes are constantly compared against any existing or incoming data and identifies relevant categories, which are further compared to data and codes (Charmaz, 2014). According to Glaser (1978), this comparison allows gaps in the data to be identified, to recognise where more information is needed. At this stage of the analysis process, concepts are elevated to a level of abstraction by naming and fitting them into categories through this iterative process (Strauss & Corbin, 1990).

Grouping the codes results in the development of categories with many containing sub-categories and together they explain the broader concept. Birks and Mills (2015) advise that a key task of grounded theory analysis is to link categories and their properties. Also, by using comparative analysis methods, the emerging categories are compared with each other to identify gaps in the data (Birks & Mills, 2011). Strauss and Corbin (1998) suggest that this phase of coding will further lead to development of relational statements which operate at a conceptually high level by integrating the categories.

Theoretical Coding and Theoretical Saturation

Theoretical coding is a sophisticated level of coding undertaken in the later stages of grounded theory analysis to move the “analytic story in a theoretical direction” (Charmaz, 2014, p. 150). It follows the codes selected by the researcher during focused coding. Glaser (2005, 2013) suggests that despite the significance of theoretical coding, it is an aspect of grounded theory analysis that researchers are most likely to struggle with. Birks and Mills (2015) suggest that how a researcher uses theoretical coding depends on the coding analysis undertaken during the second level of the coding process. They also suggest that the researcher’s reliance on theoretical coding will be greater if there is a delay in the process of identifying relationships between concepts in the theory to the advanced stages of analysis (Birks & Mills, 2015). Charmaz (2014) suggests that theoretical coding promotes clarity and precision in the final product. Glaser and Holton (2013) agree stating the developed theory will be more plausible, relevant and enhanced when integrated and modelled by an emergent theoretical code. Birks and Mills (2015) suggest that without theoretical coding, a grounded theory will not demonstrate explanatory power that differentiates it from other approaches to research.

Glaser (2013) asserts that theoretical codes must not be preconceived or forced into the analysis. Grounded theorists must avoid applying an external theory until their own theory has been developed (Charmaz, 2014; Birks & Mills, 2015; Glaser, 2013; Glaser & Strauss, 1967). Theoretical codes assist in clarifying what each category is in relation to other categories and develop theoretical links between categories and eventually links integrate into theory (Glaser, 1978).

Theoretical saturation is necessary for the integration of the final story. As suggested by Charmaz (2014), theoretical saturation should be the aim of all grounded theory researchers. Introduced by Glaser and Strauss (1967), theoretical saturation occurs when new data does not deliver new insight into the categories (Lee, 2006). Strauss and Corbin (1998) define theoretical saturation as “the point in category development at which no new properties, dimensions, or relationships emerge during analysis” (p. 143). Strauss and Corbin (1990) also suggest that theoretical saturation has occurred once the theory is well established and validated. Charmaz (2014) explains that data collection ceases when categories are saturated, when gathering new data no longer generates new theoretical insights or reveals new properties of the core theoretical categories.

3.7.2.2 The Core Category

Strauss and Corbin (1990) define a core category as “the central phenomenon around which all the other categories are integrated” (p. 116). In early seminal grounded theory publications (Glaser, 1978; Strauss, 1987; Strauss & Corbin, 1990), a central idea of core category or concept is that it encapsulates the process apparent in the categories and sub-categories constructed (Birks & Mills, 2015). According to Glaser (1978), the purpose of grounded theory is “to account for a pattern of behaviour which is relevant and problematic for those involved” (p. 93). This occurs by generating a theory around a core category that emerges from the data. In later grounded theory works and according to Charmaz (2014) and Clarke (2005), the selection of a core category is less important and instead a broader approach to describing “how categories and their sub-categories integrate together to form an abstract grounded theory of a substantive area of enquiry” (Charmaz; Clarke, as cited in Birks & Mills, 2011, p. 110).

Glaser (1978) places high importance of developing a strong, conceptually abstract category at the heart of grounded theory analysis (Birks & Mills, 2015). However, Strauss and Corbin (1990) and Charmaz (2014) take a more flexible approach to the need to identify a core category as a particular phenomenon. A core category “includes that every part of the data (emerging codes, categories, properties, and dimensions) is constantly compared with all other parts of the data to explore variations, similarities and differences in the data” (Hallberg, 2006, p. 143). Once a core category is chosen, the generation or collection of data to theoretically saturate the core and related categories and subcategories is guided by theoretical sampling (Malik., 2017). This process allows the researcher to form their grounded theory, refine and fully integrate each theoretical component, developing the overall level of conceptual abstraction (Malik., 2017).

3.7.2.3 Constant Comparative Analysis and Theoretical Sampling

Constant comparative methods "combines systematic data collection, coding and analysing with theoretical sampling with the aim of generating a theory that is integrated, close to the data, and expressed in a form clear enough for further testing" (Conrad et al., 1993, p. 280). Constant comparative methods, according to Glaser and Strauss (1967), will establish analytic distinction, therefore making comparisons at each level of analytic work. The process of constant comparison involves comparing data with initial codes to find similarities and differences and then with categories as they emerge. The emerging codes and categories are constantly checked against the data that are collected, allowing the researcher to interpretively analyse the information (Charmaz, 2006). Glaser and Strauss (1967, p. 105) write that constant comparative methodology incorporates four stages: "(1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory." The researcher, throughout the four stages, "continually sorts through the data collection, analyses and codes the information, and reinforces theory generation through the process of theoretical sampling" (Kolb, 2012, p. 83). Glaser and Strauss (1967) and Kolb (2012) emphasise the benefit of using constant comparisons is the emergence of a substantive theory from raw data.

Constant comparative methods, combined with theoretical sampling, is an important strategy used by researchers in the development of grounded theory (Glaser & Strauss, 1967; Kolb, 2012). Theoretical sampling pursues relevant data to develop the emerging theory. Charmaz (2014) writes the principal aim of theoretical sampling is to elaborate and refine the categories constituting the researcher's theory. Charmaz (2014) suggests that a common error made by researchers is confusing theoretical sampling with gathering data until the same pattern reoccurs resulting in a description of empirical themes. Instead, theoretical sampling in grounded theory gives the research analytic depth, precision and aims the researcher at "data-gathering toward explicit development of theoretical categories resulting from analyses of the studied world" (Charmaz, 2014, p. 199).

3.7.2.4 Diagrams and Memos

Diagrams and memos are essential to the analytical process (Glaser, 1978). Memos are written records by the researcher of their thoughts, reflection and ideas throughout the research

(Birks & Mills, 2015). Diagrams are visual devices that portray potential relationships between concepts (Strauss & Corbin, 1990, 1998). Along with Glaser (1998) and Strauss and Corbin (1990), Charmaz (2014) places high importance on memo-writing, “it is a crucial method as it prompts researchers to analyse their data and to develop their codes into categories early in the research process” (p. 343). Successive memos keep the research involved in the analysis and help to increase the level of abstraction of their ideas (Charmaz, 2014). Strauss and Corbin (1990) strongly advocate using diagrams from the beginning of a study concurrently with memo writing. Diagramming alongside generating or collecting data and analysing encourages the researcher to map and connect various codes in the first instance (Birks & Mills, 2015). Diagramming will assist the researcher to find gaps and holes in the developing theory which will further direct theoretical sampling (Charmaz, 2014). Birks and Mills (2015) suggest that when diagramming, the only rule is to keep a record of what has been created and throw nothing away.

3.7.3 Theoretical Integration

A grounded theory is a result of the interaction between the researcher and their data using strategies to produce saturated categories, linking concepts and categories (Birks & Mills, 2015), although there is some disagreement amongst grounded theorists on what a completed theory looks like. According to Charmaz (2014), this is due to unsettled notions about what theory means. Charmaz (2014) suggests the most dominant definitions of theory originate from positivism. Positivist definitions of theory “treat it as a statement of relationships between abstract concepts that cover a wide range of empirical observations” (Charmaz, 2014, p. 229). The aim of the positivist theory is to stress explanation and prediction, whereas interpretive theories emphasise interpretation and give abstract understanding greater priority than explanation (Charmaz & Thornburg, 2020). The aim of interpretative theories is to understand how individuals construct meanings and actions (Charmaz, 2014).

The aim of grounded theory is to explain a process or scheme associated with a phenomenon through a generated theory (Birks & Mills, 2015). As explained by Ke & Wenglensky (2010, para. 1), the objective of grounded theory is to “develop a theory that emerges from and is therefore connected to the very reality that the theory is developed to explain.” Grounded theory is about embracing a constant comparative method, conformity and coherence of codes, concepts and categories which are crucial indicators for a valid GT (Ke & Wenglensky, 2010). Glaser and Strauss (1967) introduced grounded theory as a general research program for developing substantial (reflect a specific phenomenon or situation) or formal (general in nature) theory (Scheufele, 2008). According to Glaser (1992), the final theory should be open to modification and be broad in nature, whereas Strauss and Corbin (1998, 2008) emphasise producing a dense and detailed description to explain the phenomenon. Charmaz (2014) emphasises that “when you theorise, you reach down to the fundamental, up to the abstraction, and probe into experience. The content of theorising cuts to the core of the studied life and poses new questions about it” (p. 245).

3.7.4 Reflexivity and Grounded Theory

Reflexivity as described by Gentles et al., (2014) refers to the “generalised practice in which researchers strive to make their influence on the research explicit – themselves, and often to their audience” (p. 1). Birks and Mills (2015) suggest that it is essential for grounded theorists to be reflective researchers but acknowledges what constitutes reflexivity, the value of reflexive practices and the contribution that reflexivity can make to data analysis is a topic of debate. Some researchers argue that reflexive techniques are poor-quality assurance measures and useless based on the assumption that it is impossible for individuals to attain a complete knowledge of self (Birks & Mills, 2015; Cutcliffe, 2003; Cutcliffe & McKenna, 2004). Glaser (2001) also does not support reflexivity suggesting it could lead to ‘reflexivity paralysis’ (p. 47). In contrast, Strauss (1987) suggest that researchers influence grounded theory methods and this must be recognised during the research process (Birks & Mills, 2015). Strauss and Corbin (1998) advocate the use of a reflective journal so researchers can keep a record of their metaphorical journey to learn from their experiences (Birks & Mills, 2015). Charmaz (2014) states that reflexivity must be involved in the research design to ensure the researchers’ assumptions about the world and how they influence actions are acknowledged. In this study, the researcher used the reflexivity techniques of memo-writing, methodological journal and diagrams. These concepts are discussed further in chapter four.

3.8 Constructivist Grounded Theory – The Chosen Approach

For this study, the research design was determined by the aim of the research and consideration was made to the application and feasibility of the chosen method in context of the phenomenon of interest. The aim of this research was to go beyond simple description and exploration, and rather to generate a substantive theory to understand patients' experiences of acute deterioration and MET encounter. A scoping literature review showed that little is known about the phenomenon. Therefore, the choice of grounded theory was appropriate as it results in the generation of new knowledge and a theory with explanatory power (Birks & Mills, 2015). Grounded theory methods give the researcher focus as well as systematic, yet flexible guidelines for conducting successful research (Charmaz, 2014).

The philosophical underpinnings of grounded theory research are diverse; from Glaser and Strauss's (1967) post-positivism, to the symbolic interactionist roots of Strauss and Corbin (1990), through to the constructivism of Charmaz (2006, 2012). Birks and Mills (2011) identify the importance of philosophically considering one's ontological and epistemological position and its impact on the approach to research in the context of grounded theory methodology. When exploring my philosophical position, I recognised that I believe that each person creates their own reality and that reality cannot exist without context (Denzin & Lincoln, 2011). I also believe that people construct meaning, or reality based on their interactions with the social environment and that knowledge is not found, it is constructed (Charmaz 2006, 2012, 2014). Such a position posits me in a relativism ontology operating within a constructivist paradigm. Constructivist approach is rather practical and challenges assumptions of abstract theories; the generated theory is the result of social constructions of participants and the researcher within a context. A constructivist method enables depth into the phenomenon without isolating the researcher from its context, in order to gain a deeper level of understanding of the roots of the issue being studied (Charmaz, 2006, 2014). Therefore, a CGT approach was chosen for this research.

CGT starts from the experience and inquiries about how participants create it, therefore both researcher and participant interpret the meaning and actions of this experience. In CGT the researcher assumes that both data and analyses are characterised as social construction. CGT ensures the rigor of the traditional grounded theory method, whilst fostering and encouraging empathetic understandings of participants' actions, meanings and words through openness and reflexivity (Charmaz, 2014; Ford, 2010). This study aimed to explore multiple realities which required a flexible but interpretative approach. CGT offered flexible, precise and practical methods that differ from more prescriptive approaches by Glaser and Strauss (1967) and Strauss and Corbin

(1990). As suggested by Creswell (2007), Charmaz's CGT method represents a flexible and interpretive approach to data generation and analysis, which was appropriate for this research.

3.9 Evaluating the Quality: Trustworthiness of Grounded Theory Study

According to Marrow (2005, p. 250), "qualitative research, ensuing from a variety of disciplines, paradigms and epistemologies, embraces multiple standards of quality such as validity, credibility, rigor or trustworthiness." Lincoln and Guba (2000) argue that qualitative research cannot be assessed on the positivist notion of validity, instead it should be assessed on an alternative criterion of trustworthiness (Gasson, 2004). This is justified on the basis that the positivist worldwide view differs from the interpretive view (Gasson, 2004). Therefore, different criteria or rigour and quality must "reflect the different assumptions that interpretive researchers hold about the nature of reality" (Gasson, 2004, p. 89). To assess the trustworthiness of qualitative research, Miles and Huberman (1994), Lincoln and Guba (2000) and Gasson (2004) suggest the following criteria: credibility (truth value), confirmability (representativeness of findings), dependability/auditability (reproducibility of findings) and transferability (generalisability of findings). To increase credibility and ensure trustworthiness of the research findings, there are other strategies that researchers can employ such as member checking, peer checking, and triangulation, detailed transcription, systematic plan and coding (Gunawan, 2015).

In grounded theory, Glaser and Strauss (1967) aimed to address the perceived lack of rigor in research that generated theory, although it is recognised that the evaluation criteria to assess GT studies vary. Glaser and Strauss (1967) emphasise assessing the credibility and rigor of the research in the context of the application of GT (Charmaz, 2014). They suggest that the theory should demonstrate *fit* (the field of the intended use), should be *understandable* (by those who work in the area), be *general* (flexible in application) while allowing the user *control* over its use (Birks & Mill, 2014; Charmaz, 2014; Lomborg & Kirkevold, 2003). Strauss and Corbin (1990) classify data quality, the research process and empirical grounding of the final theory as being the core components for assessing grounded theory studies. Additionally, developed theory should be assessed in terms of "the range of variation and the specificity with which they are analysed in relation to the phenomena that are their source" (Strauss and Corbin, 2008, p.18). Charmaz's (2006, 2014) criteria for assessing CGT studies are "*credibility* (familiarity within the setting or topic), *originality* (categories fresh, new insight), *resonance* (do the categories portray the fullness of the studied experience?) and *usefulness* (does the analysis offer interpretations that people can use in their everyday world?)" (p. 337-338). According to Charmaz (2014), a strong combination of credibility and originality increases usefulness and resonance, and the subsequent value of the contribution.

Table 3.1 provides an overview of the criteria proposed to evaluate grounded theory studies (Birks & Mills, 2015, p. 144).

Table 3.2: Criteria for Evaluating GT Studies

Glaser & Strauss (1967)	**Strauss & Corbin (1990)**	**Charmaz (2014)**
Fit	Data quality	Credibility
Understandable	Research process	Originality
General	Empirical grounding	Resonance
Control		Usefulness
Glaser (1978)	**Strauss & Corbin (1998)**	
Fit	Data quality	
Work	Theory quality	
Relevant	Research process	
Modifiable	Empirical grounding	
Glaser (1992)	**Corbin & Strauss**	
Fit	Fit	
Work	Applicability	
Relevant	Concepts are dense and varied	
Modifiable	Concepts are contextualised	
Parsimony	Logical flow of ideas	
Scope	Depth of findings	
	Variation within findings	
	Creativity	
	Sensitivity	
	Evidence of memos	
	13 additional criteria can also be considered.	

3.10 Summary of Chapter Three

Chapter three has presented a discussed of the philosophical underpinnings of the methodology chosen for this research. CGT methodology was discussed in detail along with the foundational tenets for data collection, data analysis and theory integration. Evaluating the trustworthiness of qualitative research and grounded theory methods was also considered. Application of the foundational tenets in the context of this research is outlined in the follow chapter.

CHAPTER FOUR

Applying Grounded Theory Methods

Chapter Four: Applying Grounded Theory Methods to Explore Patients' Experiences of Acute Deterioration and Medical Emergency Team (MET) Encounter

4.1 Introduction

Grounded Theory (GT) is concerned with psychosocial processes of behaviour and aims to explain how and why individuals behave in certain ways, in similar and different contexts (Charmaz 2006; Corbin & Strauss 2008; Dey 2008). This chapter discusses how grounded theory methods were used to explore patients' experiences of acute deterioration where a medical emergency team (MET) review occurred. Specifically, grounded theory as an emergent methodology was chosen to answer the research question:

1. What processes occur as patients experience acute clinical deterioration and MET encounter?

Constructivist grounded theory (CGT) method consists of flexible analytical guidelines that offer an interpretive portrayal of the studied world (Charmaz, 2014). The aim of constructivist grounded theory (CGT) methodology is to extend and magnify the researcher's view of the studied life, therefore deepening what is learnt and what is known about it (Charmaz, 2014). This chapter examines how CGT methods was used to explore patients' experiences of acute deterioration as well as the researcher's position in relation to the diverse paradigms of grounded theory and how this impacts theory development.

4.2 Applying Foundational Tenants of Constructivist Grounded Theory Method

4.2.1 Planning a Grounded Theory Study

A study to explore patients' experiences of acute deterioration and MET encounter was designed. To date, no such studies have been published in the Australian context. The foundation of this current study was decided after initial discussions with study supervisors, gaps in the literature and the researcher's previous clinical and research experience in the area of interest.

During the planning phase of the study, CGT methodology was found to be the most suitable approach to explore the research problem. As a novice, the researcher immersed herself extensively in the grounded theory literature, following the constructivist approach proposed by Kathy Charmaz.

4.2.2 Researcher's Philosophical Positioning

The philosophical underpinnings of grounded theory research are diverse; from the post-positivism of Glaser and Strauss (1967), to the symbolic interactionist roots of Strauss and Corbin (1990), through to the constructivism of Charmaz (2006, 2012). Birks and Mills (2011) identify the importance of philosophically considering one's ontological and epistemological position and its influence on the approach to research in the context of grounded theory methodology (GTM). In questioning my philosophical position, I identified that I was driven by the belief that each person creates their own reality, and that reality cannot exist without context (Denzin & Lincoln, 2011). I also believes that individuals or groups construct meaning, or reality based on interactions with the social environment (Charmaz, 2006, 2012, 2014) and that knowledge is not found, it is constructed. Such a position posits me in a relativism ontology operating within a constructivist paradigm. Therefore, from the planning phase of this research, Charmaz's constructivist approach was followed. Being an experienced clinician, I acknowledged my assumptions regarding the area of interest and challenged these throughout the research.

4.2.3 Data Collection Methods

Gathering rich data provides researchers with solid material for building a significant analysis (Charmaz, 2006). Rich data is considered detailed, focused, and reveals participants' views, feelings, interactions, and actions as well as the contexts and structures of their lives (Charmaz, 2006, 2014). The founders, Glaser and Strauss, called the method "grounded" because a theory was generated from a broad array of data through a rigorous process of constant comparison (Glaser, 1992; Glaser & Strauss, 1967; Stern, 1980). To understand how research participants, construct and define their realities in the social context, grounded theories may be developed with diverse kinds of qualitative and quantitative data (Lee, 2006). Charmaz (2014) asserts that a study's credibility is determined by the relevance, substance, scope and depth of the data.

The choice of data collection methods for this study was guided by the underlying philosophy of grounded theory methodology, and research aim and question. Therefore, the most appropriate data collection method chosen for this study was one-on-one interviews. This is discussed in detail in the following section.

4.2.3.1 Interviews

Intensive interviews were the chosen method of data collection for this research. In qualitative research, interviews are the most common method of gathering data (Savin-Baden & Howell Major, 2013). According to Birks and Mills (2015), in GT research, "the value of interviewing is evidenced by the extensive number of studies that rely on it as a principal mechanism for the generation of data" (p. 72). Charmaz (2014) explains that, interviewing in grounded theory is a conversation between a participant and researcher that explores a participant's personal experiences related to a research topic. According to Charmaz (2014, p. 56), the key characteristics of intensive interviewing include:

- "Selection of research participants who have first-hand experience that fits the research topic.
- In-depth exploration of participants' experiences and situations.
- Reliance on open-ended questions.
- Objective of obtaining detailed responses.
- Emphasis on understanding the research participant's perspective, meanings and experience.
- Practice of following up on unanticipated areas of inquiry, hints, and implicit views and accounts."

Qualitative research draws on investigative, intensive and informational interviewing strategies (Charmaz, 2014). The aim of informational interviewing is to gather accurate facts and descriptions of events with clarification about places and those involved (Charmaz, 2014). Investigative interviewing also aims to gather accurate details but it's purpose is to uncover hidden actions and intensions or exposing policies and practices and their implications (Charmaz, 2014). Whereas intensive interviews create and open an interactional space where a participant's experience can be explored and meanings interpreted (Charmaz, 2014). It is a useful method for interpretive inquiry to "understand the research participant's language, meanings and actions, emotions and body language" (Charmaz, 2014, p. 57). The in-depth nature of intensive interviews foster the participant's interpretation of their experience at the time the interview takes place (Charmaz, 2014). By using intensive interviews, the constructivist mode of GT encourages the researcher to enter the world that is being studied and to learn from the inside (Hallberg, 2009). In their later work, Strauss and Corbin (1998) acknowledged the co-construction of meaning between the participant and researcher, which is implicit during the interview process (Kolb, 2012). Mills et al., (2006) suggest that during the narrative process, the researcher and participant give and take from each other creating a site for co-construction of knowledge, leading to results that are both mutually negotiated and contextual (Collins, 2005; Fontana & Frey, 2000; Hand, 2003; Reinharz, 1992). According to Guba and Lincoln (1989), "it is impossible to separate the inquirer from the inquired into. It is precisely their interaction that creates the data that will emerge from the inquiry." (p. 88)

This current study was granted ethical approval from the human research ethics committees of Federation University (Appendix 1a), Monash University (Appendix 1b), Ballarat Health Service (Appendix 1c), Latrobe Regional Hospital (Appendix 1d) and St John of God Health Group (Appendix 1e). Following receipt of ethical approvals, data collection commenced in May 2018. In line with the study question, and by employing purposive sampling, patients who experienced acute deterioration and been cared for by a MET were invited to participate. Ethical considerations specific to this study are discussed later in this chapter.

Data were collected at three hospital sites: Ballarat Health Service (BHS), Latrobe Regional Hospital (LRH) and Central Gippsland Health Service (CGHS). Patients over 18 years of age who experienced acute deterioration resulting in a MET review were invited to participate. Patients were excluded if they were confused and/or unable to provide informed consent, English was not their first language, assessed as clinically unstable by a hospital clinician, an obstetric patient, had an active complaint against the hospital, a mental health unit inpatient or under a mental health team. Once a patient met the inclusion criteria, they were provided with a plain language information statement (Appendix 2a) and consent form (Appendix 2b). Potential participants were approached in accordance with hospital ethics requirements. This approach differed between the three hospital sites. At Ballarat Health Service the researcher was approved to approach potential participants whereas, at Latrobe Regional Health and Central Gippsland Health Service patients were approach by a nominated hospital clinician as requested by the ethics committee. After receiving information about the study, potential participants were followed up regarding their interest in being involved in the research. At this time, further explanation of the study was provided, details were clarified, and any questions were answered by the researcher. Individuals who chose to participant in the research returned consent forms agreeing to partake in a recorded interview.

Once a participant consented to be interviewed, a mutually agreeable time and place was agreed upon. Altogether 27 interviews were conducted, 24 occurred at the patient's bedside with three conducted in the ward's visitors room to ensure privacy as the participant was in a shared room. Participants were interviewed one-on-one, using a semi-structured format with some guiding questions (Appendix 5). Interviews were approximately 30 minutes in duration, were audio recorded and later transcribed verbatim. Each interview began by outlining the study purpose, reiterating the explanatory statement, ensuring the protection of their identity and how the information gathered would be stored.

For the current study, an interview guide was developed which underwent a peer and supervisor review process. The interview guide helped the researcher prepare for conducting the interview, to achieve the research objectives and to have better control of how and when to ask questions during the conversation (Charmaz, 2014; Holloway, 2005). Charmaz (2014) recommends that an interview guide should be a flexible tool that assists researchers become aware of their own interests, assumptions and use of language. An initial interview guide should be provisional and modified as concepts begin to emerge (Birks & Mills, 2015; Strauss & Corbin, 1998). Karp (2009) considers the development of an interview guide a point in the research process where 'analytic motifs and ambitions' of the research can be clarified (p. 40). It provides the researcher with an opportunity to set out the domains of inquiry (Karp, 2009; Ralph, 2013). Charmaz (2014) argues that without an interview guide a novice researcher may unintentionally force interview data into preconceived categories, which undermines a grounded theory study. In the beginning, the researcher used a guiding question (Appendix 5) to reveal participants' understandings and experiences, for example:

I understand you became unwell and needed to be reviewed and cared for by the hospital's medical emergency response team. Can you describe for me your experience?

Beginning the interview with an open-ended, non-judgemental question, encouraged unanticipated statements and stories to emerge from the participant's experience (Birks and Mills, 2015; Charmaz, 2014). The interview questions became more focused to elicit and elaborate the participant's experiences and to link emerging concepts and categories (Charmaz, 2014). As suggested by Charmaz (2014), the questions within the interview guide were developed by the researcher who listed topics that could address the research question and objectives. This also allowed the interviews to be flexible and spontaneous. Charmaz (2014) suggests when starting a new project without an interview guide and guiding questions, it is fraught with danger. Novice researchers may ask 'awkward, poorly times, intrusive questions that you may fill with unexamined preconceptions' (Charmaz, 2014, p. 63). As guided by Charmaz (2014), the questions were framed to 'reflect a symbolic interactionist emphasis on learning about participants views, experienced events, and actions' (p. 65).

The interviews were audio-recorded, with permission of the participants. The researcher listened to each audio-recording several times to identify and understand the meaning of the participants' experiences beyond what they expressed. In seminal works, Glaser (1998) argues that recording interviews detracts from the focus of early categories and generates a substantial amount of superficial data. In contrast, Birks and Mills (2015) suggest that recording interviews provides additional security for valuable data and allows verbatim quotations to be used to defend codes and illustrate the final theory. Charmaz (2014) argues that recording interviews preserves rich details such as the participant's tone and tempo, silences and statements as well as the form and flow of questions and responses. As a novice researcher and having had minimal prior experience in interviewing, the researcher conducted practice interviews with peers before data collection began. This reflective process allowed the researcher to gain confidence in conducting intensive interviews, practise interviewing techniques and modify the interview guide. In the beginning, interviewing appeared to be intensive, but at times, the flow of the conversation was disrupted by the researcher asking somewhat related questions to fill silences or force discussion. To address this for future interviews, the researcher engaged in reflective processes and received guidance from study supervisors. Engaging in reflective processes after each interview, allowed the researcher to better draw implicit meanings, assumptions, definition of terms, situations and events from the participants' experiences.

Interviewing practices within the constructivist paradigm differ from traditional grounded theory approaches. Constructivist grounded theorists view interviewing as emergent interactions in which social bonds may develop (Charmaz, 2014). It allows for the mutual co-construction of knowledge based on the participant's experiences, silences, interviewer-participant relationship and the interview content (Charmaz, 2014). Hiller and DiLuzio (2004) view the constructivist approach to interviewing as a site for exploration, emergent understandings and validation of experiences. CGT emphasises going into the emergent phenomena and defining their properties (Charmaz, 2014). Additionally, the researcher is encouraged to move back and forth between the data to form their analysis as an iterative process, leading to pursue additional events, processes, experiences and stories (Charmaz, 2014). In this current study, based on the participants' stories, the researcher was able to build 'what' and 'how' questions into the data collection. According to Charmaz (2014), these questions elicit content and begin to shape a subsequent theoretical analysis.

In the current study, purposive sampling was employed to target patients who were thought to be appropriate for this study. Purposive sampling enhances the likelihood of uncovering a wide range of realities (Strauss & Corbin, 1998). As the researcher progressed and important concepts from the participants' perspectives began to emerge, theoretical sampling was undertaken (Hall et al., 2013). When engaging in theoretical sampling, the researcher pursues people, events or information to illustrate, define and explain properties, boundaries, and relevance of the category or set of categories (Bryant & Charmaz, 2019; Charmaz, 2014). In this study, as categories began to develop, further data were collected to develop the emerging categories and their properties. Therefore, theoretical sampling allowed categories to fully develop, elaborate their meanings, clarify relationships between categories, assist in seeking new theoretical renderings and define gaps to fully explore a range of processes in relation to patients' experiences. Hence, the emerging categories guided the dynamic process of data collection and analysis (Hall et al., 2013).

How many interviews a grounded theorist should conduct remains contested. Strauss and Corbin (1998) suggest that data collection can cease once no new data appears and all concepts of the theory are well developed. Both Glaser (2001) and Charmaz (2006) emphasise that data collection should continue until "conceptualization of comparisons of these incidents which yield different properties of the pattern, until no new properties of the pattern emerge" (Glaser, 2001, p. 191). Charmaz (2014) clarifies that grounded theorists should aim not to saturate data, instead to saturate emergent categories and concepts. In this study, concurrent data collection and analysis occurred until categories had been fully developed and the researcher was confident that categories were fully saturated. The sample size for this study was considered satisfactory when emerging categories from the data reached saturation and further data collection did not produce any new information or concepts (Morse, 2000). In total, 27 interviews with patients were conducted across three Victorian health services. After the twenty-third interview, the reoccurrence of themes was noted; however, to further elaborate categories and verify emerging concepts, four additional interviews were included.

Of the 27 recorded interviews, thirteen were transcribed by the researcher and the remaining interviews were professionally transcribed. A professional transcription service was employed once the researcher felt confident in her ability to transcribe interviews and to save time. The interviews that were professionally transcribed were checked against the original recording to ensure accuracy and any errors were corrected before initial coding occurred. Some interviews (four) were subject to member checking, a technique used to confirm that interpretations align with participants' meanings and experiences (Wong et al., 2017). Although, according to Birks and Mills (2015), Charmaz (2014) and Sandelowski (2002) member checking is not necessary, as grounded theorists believe participants' understandings about their worlds are not static entities and instead subject to change and are influenced by the context of the moment. Memos and journal entries were made after each interview was conducted and were revisited after the researcher listened to each recording. The researcher made every effort to analysis the interview data before the next interview. However, this was impossible in some instances due to minimal time between interviews. Therefore, in some cases, a preliminary analysis was performed before the next interview occurred.

To adhere to the principles of CGTM, the researcher kept records of conceptual ideas in the form of memos and an audit trail of decisions made to reach theory development.

4.3 Data Analysis Approach

GT is a rigorous method that enables researchers to construct conceptual frameworks or theories through inductive theoretical analysis (Corbin & Strauss, 2008). Data analysis commences with basic description, moves to conceptual ordering and then on to theorising (Patton, 2002; Walker & Myrick, 2006). GTM requires the researcher to be fully immersed in the data to understand how and why people behave in certain ways, in similar and different contexts (Charmaz 2006; Corbin & Strauss 2008; Dey 2008). According to Charmaz (2014), constructivist grounded theorists "aim for abstract understanding of studied life and view theory analyses as located in time, place, and the situation of inquiry" (p. 342). To become proficient in data analysis, the researcher was guided by techniques suggested by Kathy Charmaz (2014) and research supervisors.

4.3.1 Engaging with Initial Coding

Coding is not simply part of data analysis; it is the "fundamental analytic process used by the researcher" (Corbin & Strauss, 1990, p. 12). GT coding is different from other types of coding because it codes for actions, invokes comparative methods, and discerns meanings through exploring events and actions (Charmaz & Bryant, 2011). By conducting initial coding, the researcher began to form links between collecting data and developing an emergent theory to understand and account for the data (Birks & Mills, 2015). According to Walker and Myrick (2006), "it is what transports researchers and their data from transcript to theory" (p. 549). The researcher approached initial codes as provisional, comparative, and grounded in the data, an approached recommended by Charmaz (2014). During the analytical process, Charmaz (2014) firmly believes in using gerunds (noun form of the verb) as it assists the researcher to identify actions and processes within the data, rather than focussing on the individual. Gerunds help to describe what is occurring in the data, identify the code's theoretical direction, and distinguish lines of emerging story in the data (Charmaz & Bryant, 2011). In the current study, the researcher remained close and immersed herself in the data by reading through interview transcripts and field notes. As suggested by Charmaz (2014), the researcher attempted to code the data as *actions* to avoid focusing on individuals' tendencies. Throughout initial coding, the researcher remained open to exploring theoretical possibilities, which helped to define categories.

4.3.1.1 Performing Line-By-Line Coding

Line-by-line coding helps to define implicit meanings and actions. It prompts the researcher to study each line of the data and begin to gain a conceptual handle of them (Charmaz, 2014; Charmaz & Bryant, 2011). In the current study, each interview transcript was analysed using line-by-line coding. The data were fragmented and coded using verbs and gerunds to define actions and processes. As stated by Charmaz and Bryant (2011), conducting line-by-line coding using gerunds helps to capture, form, and connect fragments of data.

During line-by-line coding, the researcher remained open to the data to identify implicit concerns, as well as explicit statements. This coding process was guided by flexible strategies suggested by Charmaz (2014, p. 125): "*breaking the data into their component parts or properties; defining the actions on which they rest; looking for tacit assumptions; explicating implicit actions and meanings; crystalising the significance of the points; comparing data with data; and identifying gaps in the data."* By using these strategies, it encouraged the researcher to explore theoretical possibilities and create codes that best fit the data (Hall, 2013). An attempt was made to be critical towards the data to see actions and to identify significant processes. Charmaz (2014) suggests that being critical encourages the researcher to ask questions about the data. When critically analysing the data the researcher was guided by the following questions: "*What process (es) is at issue here? How can I define it? How does this process develop? How does the research participant act while involved in this process? What does the research participant profess to think and feel while involved in this process? What might his or her observed behaviour indicate? When, why, and how does the process change? What are the consequences of the process?"* (Charmaz, 2014, p. 127). As the codes evolved, constant comparative analysis was conducted, and gaps were identified. To address these gaps, the researcher used theoretical sampling to direct further inquiring to gather information-rich data, this allowed for data collection and coding to become more focused. Line-by-line coding enabled separating data into categories and to see processes, which were further analysed through focused coding.

Glaser (1978, 1992) firmly believes when conducting initial coding the researcher should not have any preconceived ideas. Dey (1999, 2008) and Charmaz (2014) disagree and instead encourage researchers to examine how their past influences the way they see the world and the data by embracing their prior skills and ideas. In the current study, the researcher maintained a reflexive journal to identify any personal and professional assumptions that potentially could have influenced the development of codes and findings.

4.3.2 Category Formulation Through Focused Coding

In CGT methodology, the second major analytical phase is focused coding. During focused coding the most significant and frequent codes discovered during initial coding are used to examine, organise, synthesis, and analyse large amounts of data (Charmaz, 2014). Focused codes advance the theoretical direction of the research and are more conceptual than initial codes (Glaser, 1978). In the current study, the researcher conducted focused coding by assessing and studying initial codes, aiming of determine their adequacy and conceptual strength. Initial codes were compared with the data to distinguish which codes had greater analytical power. This process further directed the analysis and resulted in the development of promising tentative categories. The categories were compared with codes and concepts to determine their relevance which also identified further gaps in the data. To address and fill these gaps theoretical sampling was conducted. Using Charmaz's approach to analysis, the researcher was guided by the following questions when conducting initial and focused coding:

1. "What do you find when you compare your initial codes with date?
2. In which ways might your initial codes reveal patterns?
3. Which of these codes best account for the data?
4. Have you raised these codes to focused codes?
5. What do your comparisons between codes indicate?
6. Do your focused codes reveal gaps in the data?" (Charmaz, 2014, p. 140)

As focused coding proceeded, the researcher began to identify explanatory and conceptual patterns in the analysis which led to the formation of provision categories. These categories were multi-dimensional and consisted of a number of sub-categories that together explained the broader concept. Focused coding moved the analysis into a theoretical direction where relationships between categories and concepts were created. During this phase, the researcher discovered incidents, interactions and perspectives that had not previously been considered. During initial and focused coding, Charmaz (2014) encourages researchers to ask the following question: "what kind of theoretical categories do these codes indicate?" (p. 144). By reflecting on this question, the researcher was able to conceptualise material that initially was inadequately theorised, therefore, gaining theoretical sensitivity about codes and emerging concepts. Finally, three categories were constructed: *Experiencing changes - before the encounter, Perceiving the reality - the encounter* and *Reflecting on the event - after the encounter*. Tables 4.1 and 4.2 provide an overview of data analysis steps undertaken, and an audit trail for a category, *Reflecting on the event – after the encounter*. A detailed discussion of the categories and how they were constructed is provided in chapter five.

Table 4.1: Overview of Data Analysis Approach

Initial Coding
• Interviews were transcribed into transcripts. • Line-by-line analysis was performed. Transcripts read multiple times to identify actions, processes, consequences, and causes. • Labels were assigned to each line on transcripts and directed by questions such as: “What is going on?” “What is being said here”? “What does the participant mean”? “Who is involved?” and “Into what context?”, “What process do they suggest”? “When, why and how does the process change” (Charmaz, 2006; 2014, p.127). • Data were compared to other data and codes. • Further data collection was directed by emerging concepts and codes (theoretical sampling) • Memo writing continued. • Discussion with research supervisors.
Focused Coding
• Identified codes and concepts were raised to an advanced level-focused codes. • Identified focused codes were constantly compared with initial codes, data and with emerging concepts. • Relationships between the concepts were explored. • Concepts were raised to construct sub-categories and the sub-categories were compared with data to seek relevance, and fitting. • Sub-categories were further raised to a level where the emerging categories could be examined. • Each category was constantly compared with the data, codes, and sub-categories. • A concept map was generated to examine the link between the sub-categories and categories. • Memo writing continued. • Discussion with the research supervisors.
Theoretical Coding
• The emerging categories were further refined and examined against data until a core process/category was identified. • The core category was refined and integrated to a higher level of abstract explanation in a form of theory, grounded in data. This further provided the linkages between categories and the core process. • Theoretical model was used to explain the relationship between theoretical construct, its transitional stages, categories, sub-categories, and contextual conditions. • Memo writing continued.

- Discussion with the research supervisors.
- Generated theory and the model explaining categories and contextual determinants were discussed with two study participants.

Table 4.2: Audit Trail for the Category – “Reflecting on the Event – after the encounter”

Examples of raw data	Coding	Subcategories	Category
“Up until then (MET review) I was cruisy, accepting every day as it came. After that I lost my confidence and I panic more now when I have trouble breathing…”	Coming to terms with new self-awareness	Experiencing an impact	Reflecting on the event – after the MET encounter
“It has made me more aware and I ask the nurses all the time to check my stats, when they do and they are ok I feel reassured.”	Being made aware		
“It’s opened up my eyes to how serious things are, how serious my breathing is, to the extent that I have started to see a psychologist here.”	Realising the seriousness		
“It made me realise I am sick…and how precious life is.”	Realising life is precious		
“They tend to disperse…they don’t answer any questions, they are ready to move on”	Asking questions	Seeking an understanding	
“I think that after the MET call they tend to disperse and you want to know what happened but they don’t answer any questions, they are ready to move on…”	Wanting to know what happened		
“When you’re in situations like that you don’t know what is going to happen but you’ve just got to accept it, can’t do nothing about it.”	Accepting what happened	Accepting of events	
“I have been deteriorating lately. I accept that and I accept what happened (the MET review). It’s not often that I accept things like that.”	Learning to accept		
“I have accepted a lot of things along the way and I know what’s going to happen and all of that when a MET is called.”	Accepting what has and will happen		
“…there was only one point, they were so busy talking about me they didn’t pay attention to me…I was throwing up [vomiting] and all I wanted was a tissue.”	Wanting to be seen	Wanting to be seen	
“…mustn’t lose sight of the fact that the patient is actually a real person that doesn’t have their knowledge and their expertise.”	Losing sight of the person in the bed		
“…recognise that even though the patient can’t articulate, that they are still in there and listening…”	Wanting to be seen		
“They (MET) are here to help you and make you comfortable, so just go with the flow.”	Advising to go with the flow	Advising others	
“…go with the flow, be guided by them, they are the professionals…”	Being guided by professionals		
“Just take the advice, let them do their job…”	Taking advice		
“Don’t hang about at home for too long. I mucked around a bit about whether I should have come in or not and I should have. Definitely come in quicker.”	Advising not to hang about Being indecisive		
“Do not hesitate…if you’re feeling a bit strange, ring your bell, tell your nurse. I should have the first time…”	Advising not to hesitate		
“Try to keep yourself positive as much as possible. Remember that your body may be sick but your brain is not.”	Advising to keep positive		

4.3.3 Theoretical Coding

Theoretical coding follows the codes selected during focused coding and is considered a sophisticated level of coding (Charmaz, 2006, 2014). In the current study, theoretical coding was used in the later stages of analysis to move the 'analytic story in a theoretical direction' (Charmaz, 2014, p. 150). Glaser and Holton (2007) suggest that, although theoretical coding is not necessary for theoretical development, by conducting this phase of analysis it will promote clarity and precision in the final product. According to Birks and Mills (2015), without theoretical coding, a grounded theory will struggle to demonstrate the explanatory power. The researcher used theoretical coding after the substantive coding process to examine the relationships between and among the categories. Ralph et al. (2014) suggest that theoretical coding must be undertaken once categories are formed as it would be "forceful and presumptive to conceptualise relationships before they are formed in the data" (p. 121).

A concept map (Appendix 8) was developed to identify relationships between each category and generated code. During this stage of analysis, the researcher confirmed saturation of the theoretical categories as established properties accounted for patterns within the data and no new concepts were revealed (Glaser, 1978; Holton, 2007; Wiener, 2007). To determine if the categories were fully saturated the following questions were considered:

1. "Which comparisons do you make between data within and between categories?
2. What sense do you make of these comparisons?
3. Where do they lead you?
4. How do you comparisons illuminate your theoretical categories?
5. In what other directions, if any, do they take you?
6. What new conceptual relationships, if any, might you see?" (Charmaz, 2014, p. 214)

4.3.4 Performing Constant Comparative Analysis

Constant comparative analysis is an essential method to data analysis and theory integration (Charmaz, 2014). It involves comparing incident with incident, incidents with codes, codes with codes, and categories with categories. In the current study, the substantive theory developed was dependent on the constant comparative method and the researcher's handling of the data. The constant comparison throughout data analysis influenced theoretical sampling and the ongoing generation of data. It is this iterative analytical method of constant comparison that resulted in high-level conceptually abstract categories, rich with meaning (Basnyat, 2018).

4.3.5 Memo-Writing, Methodological Journal and Diagrams

Memo-writing is a critical method in GT as it encourages the researcher to analyse data and code early in the research process (Birks & Mills, 2015). It is an essential intermediate step between data collection and theory integration. Charmaz (2014) describes memo-writing as a method that captures the researcher's thoughts, comparisons, connections and directions to pursue. It creates an interactive space where the researcher can question the data, codes, ideas and feelings. Memos have been described as "intellectual capital in the bank" (Clarke, 2005, p. 85). In the current study, memo writing occurred throughout the research process and notes were written describing the researcher's thoughts, feelings, concerns, reflections, participants' actions and any issues identified (Appendix 6 for examples). As suggested by Clarke (2005), a central memo bank was created, memos were handwritten and cross-filed as ideas were refined. Memo-writing helped the researcher to acknowledge her own assumptions, relate categories, and engage with constant comparative analysis which transformed data into theory (Seibold, 2020). Additionally, by memo-writing the researcher was able to improve subsequent data gathering and engage in critical reflexivity.

A methodological journal is a log where methodological dilemmas, directions and decisions are stored. Additionally, a methodological journal can prompt ideas for memos. As recommended by Charmaz (2014), the researcher kept a journal to engage in reflexivity and to avoid importing prior experiences and assumptions into the data (Appendix 7 for examples). The researcher noted that keeping a journal allowed her to take a new look at a familiar environment, to reflect on the interviews soon after they occurred, to develop ideas during data collection, to review previous data and make comparisons with recent interviews and create useful memos that informed the analysis.

Diagrams are a visual representation that can assist in the process of data analysis (Birks & Mills, 2015). In the current study, concept maps (Appendix 8) were developed to provide a visual representation of categories and their relationships. This assisted the researcher to visualise and understand the relative scope, power and direction of the categories, as well as the strength and weakness of the relationships (Hall, 2013).

4.3.6 Constructing the Theory

GT goes beyond describing a phenomenon, the final product is an integrated and comprehensive GT that explains a process or scheme (Birks & Mills, 2015). Strauss and Corbin (1998) define theorising as "the act of constructing from data an explanatory scheme that systematically integrates various concepts through statement of relationship" (p. 25). However, Charmaz (2014) asserts that theorising is more than explaining the interpretive work, it is about gaining “an understanding of how participants construct meanings and actions in specific situations” (p. 239). Despite the differences in perspectives, grounded theorists go beyond simply describing a phenomenon, instead they develop a set of plausible relationships between concepts and categories that clarify what is happening (Birks & Mills, 2015; Hall et al., 2013)

In this study, the theoretical model ‘*Unravelling a complex experience: contextualising patients’ experiences of acute clinical deterioration and Medical Emergency Team (MET) encounter*’ (Appendix 8) emerged, offering a possible explanation of patients’ actions and processes. This model, which explains the relationships between categories, sub-categories and contextual factors influencing them, is presented in the theory chapter. This theory offers interpretation and understanding of patients’ experiences instead of prediction and explanation, therefore, meeting the proposed criteria by Charmaz (2014). Interpretive theories assume multiple realities, provide meanings to those realities and are fully compatible with Mead’s view of symbolic interactionism (Charmaz, 2006; Malik, 2016). When the theory was constructed, two participants were contacted to discuss the theory. They confirmed the developed theory was a true interpretation and representation of participants’ meaning in a specific context.

In constructing theory that is well grounded in data, Charmaz (2014) outlined four theoretical constructs to consider, namely: theoretical plausibility, theoretical direction, theoretical centrality and theoretical adequacy. According to Charmaz (2014), when developing a GT from interview, theoretical plausibility is more important that accuracy which many qualitative researchers desire. In this study, theoretical plausibility of ideas occurred in the early stages of the research by gathering in-depth and broad natured data. Theoretical direction occurred as the study progressed and codes began to emerge. Coding processes and memoing directed the researcher towards future data collection by focusing on questions and events to explore. Theoretical centrality was pursued once theoretical direction developed. Emerging categories, as a result of focused coding, guided the researcher to gather more data to develop the properties within the categories (theoretical sampling). Theoretical adequacy occurred in the later interviews by asking specific question and gathering data to saturate emerging categories. Additionally, the researcher was immersed in concurrent data collection and analysis procedure that ensured theoretical direction, centrality and adequacy was achieved.

Trustworthiness of the study findings was established by collecting multiple perspectives of the phenomenon in the form of one-on-one and face-to-face interviews. This ensured the developed categories represented the meanings and interpretation of participants’ experiences, actions, emotions and body language which enhances the study credibility. Credibility was also confirmed by discussing the study findings with research supervisors, member checking and when reporting the findings, using participants own words. The criteria of transferability and dependability was achieved by maintaining an audit trail that demonstrated the constructed codes, categories and resultant theory, as well as memoing. Chapter Nine discusses in full detail how rigour was established using evaluation criteria proposed by Charmaz (2006, 2014).

4.4 Ethical Considerations

The World Health Organisation [WHO] (2018) states, "it is important to adhere to ethical principles in order to protect the dignity, rights and welfare of research participants." The National Health and Medical Research Council (NHMRC) developed a comprehensive set of guidelines known as *The National Statement on Ethical Conduct in Human Research* to ensure high quality research is conducted. In Australia, human research is governed by law that establishes rights for participants and imposes general and specific responsibilities on researchers and institutions (NHMRC, 2018). In studies involving human participants, researchers' primary ethical focus is a duty of care towards research participants and to ensure the integrity of the research process. In this study, an ethics application was submitted to three hospital ethics committees and the University's ethics committee for human research. Following some minor amendments, approval was granted.

The values and principles of ethical conduct in human research outlined by the NHMRC (2018) guided this research. According to the NHMRC, the values help to shape the relationship between researcher and participant to one of trust, mutual responsibility and ethical equality (NHMRC, 2018). These values are *research merit and integrity, justice, beneficence, and respect*. To ensure *research merit and integrity*, the research and method chosen was appropriate for the type of participant as they were able to comprehend the requirements of this study and provide informed consent. *Justice* was addressed by ensuring participants had read and understood the explanatory statement before agreeing to participate in the research. *Beneficence* was ensured by allowing participants an independent choice on when the interviews would occur and providing emotional support during and after the interviews were conducted. *Respect* was ensured by gaining ethical approval before the study commenced, explaining the research and likely outcomes, obtaining informed consent from participants and respecting an individual's decision not to participate in the study.

4.4.1 Obtaining Informed Consent

Informed consent is a voluntary agreement and a pre-requisite for any individual to participate in research without any threat or fear. The principles of informed consent are to protect the dignity and rights of the participant and minimise the risk of harm (Gibson et al., 2012). The NHMRC guideline (2018) states that "a person's decision to participate in research is to be voluntary and based on sufficient information and adequate understanding of both the proposed research and the implication of participation in it" (p. 19). Adequate information of the study's purpose, methods, demands, risks and potential benefits must be presented in a suitable way to each participant with the aim of ensuring a mutual understanding between the researcher and participant (NHMRC, 2018). Gibson et al. (2012) state continued consent cannot be assumed and must be regularly revisited. It must be made clear to participants that they have a right to withdraw from the study at any time and not just at the initial signing of paperwork (Shahnazarian et al., 2008).

4.4.1.1 Disclosure of study information

To ensure important aspects of the informed consent process were met, an explanatory statement and consent form were distributed to potential participants (Appendix 3a-4b). Before the consent form was completed, the researcher ensured that potential participants had read the explanatory statement, had sufficient understanding of the study's purpose and any concerns, if raised, were addressed. If the participant had not read the explanatory statement and did not demonstrate a sufficient understanding of the study's purpose, the researcher shared essential aspects of the study and gave the potential participant adequate time to consider participation. During this process, and prior to interviews being conducted, participants were assured that participation in the study was voluntary and they could withdraw at any stage. Interviews were conducted only once written consent was obtained.

It was identified that minor inconvenience may be experienced by participants as a result of the interview process. Participants were assured that if they experienced any discomfort during the interview they could stop at any time. Qualitative interviews have limitations that sometimes they could provoke anger or distress which requires time from both ends to work through, instead of a sudden termination of interview (Kvale & Brinkmann, 2009), however this did not occur. The researcher provided the contact details for counselling services on the explanatory statement for participants should the need arise. The researcher was honest and made clear to participants the time required to be engaged in interview and observation.

4.4.1.2 Voluntary Consent

As stated in the *National Statement on Ethical Conduct in Human Research*, no person should be subjected to coercion or pressure in deciding whether to participate (NHMRC, 2018). Coercion involves "a *threat* to violate someone else's rights in order to obtain compliance in situations where that person has no reasonable alternative but to comply" (Largent & Lynch, 2017, p. 2). In the current study, participants were not forced to participate in the research nor offered any financial benefits. Potential participants were approached in accordance with hospital ethics requirements. This approach differed between the three hospital sites. At Ballarat Health Service the researcher was approved to approach potential participants whereas, at Latrobe Regional Health and Central Gippsland Health Service patients were approach by a nominated hospital clinician as requested by the ethics committee. No matter the approach, care was taken to ensure potential participants not only met the inclusion criteria but were assessed as clinically stable by hospital clinicians (ICU liaison nurse or clinical educator, Nurse Unit Manager or Associate Unit Manager & bed side nurse). Participants were free to make decisions based on their willingness to participate upon receiving the study information. Voluntary consent was obtained once all the essential information was provided, the participant demonstrated sufficient understanding of the study's purpose and any questions or concerns were addressed. Interviews were conducted once written consent was obtained.

4.4.2 Right to Anonymity and Confidentiality

Anonymity and confidentiality are crucial to ensure that participants feel safe in revealing personal information. In research, a priority is to protect the privacy of those who voluntarily agree to participant in research (Gibson et al., 2012). Confidentiality refers to "separating or modifying any personal, identifying information provided by participants from the data" (Coffelt, 2017, p. 227), whereas anonymity refers to collecting data without obtaining any identifiable or personal information from the participant. Coffelt (2017) explains that if identifiable information is provided, on a consent form for example, the information needs to be separated from the data. Researchers have an ethical responsibility to ensure research participants are not identifiable and the information they provide is not traced back to them in any forms of dissemination (Coffelt, 2017; Crowe et al., 2008). During the design of a study, the process of data collection and analysis, several aspects of confidentiality and anonymity are warranted. A violation of confidentiality occurs when a research participant's identity is deliberately or accidently revealed to a person who is unauthorised to access the data.

In this study, participants learnt about anonymity or confidentiality via the explanatory statement, informed consent document and discussion with the researcher. The data was not collected anonymously or kept confidential as verbatim quotes are used in the thesis. Instead, all information obtained from the participants was not identifiable throughout each stage of the research process. Interviews were transcribed and pseudonyms were assigned to each transcript.

During the analysis process, transcripts with pseudonyms were provided to study supervisors. Study results are also reported using pseudonyms.

4.4.3 Right to Protection from Discomfort and Harm

The protection of participants in any research is absolute, with all research involving humans undergoing strict peer review processes conducted by ethics committees (NHMRC, 2018). For example, being interviewed on a sensitive topic and at length can be upsetting and intrusive (Gibson et al., 2012). Applying the ethical principle of beneficence, the welfare of participants in this study was a priority and the aim was to minimise the risk of harm or discomfort. Potential participants were identified by a nominated hospital clinician using the inclusion criteria (Appendix 2). Before the potential participant was approached, the researcher discussed the patient with the Nurse Unit Manager (NUM) or Associate Nurse Unit Manager (ANUM) and the patient's bedside nurse to ensure the patient was clinically stable. If any clinician consulted felt the patient was not appropriate, they were not approached. For patients deemed appropriate, they were approached in accordance with hospital ethics and provided with the explanatory statement and consent form. For those patients who participated in the study, a follow-up phone call was conducted one week after the interview to provide any support if required. At no time during the data collection process, or follow-up phone call, did a participant express discomfort or harm by participating in this research. At no time during the interview process did a participant disclose unprofessional conduct by their treating MET. If a participant revealed a breach of professional conduct, the researcher would ensure confidential reporting to an appropriate hospital authority occurred.

4.4.4 Storage of Data

The *Australian Code for the Responsible Conduct of Research* provides broad principles for a foundation of high-quality research, credibility and community trust in research (NHMRC, 2018). Specifically, the principles outline the responsibilities of researchers to ensure data and datasets are properly managed. In this study and in accordance with university's policy, all electronic data (interview recordings and transcripts) are stored on a password protected computer and USB. All hard copy data (consent forms, transcripts) are secured in a locked filing cabinet in a locked office on university premises for a minimum of five years from the completion of the project. After this time, all information concerning the research will be stored permanently in a Federation University central repository or distribution system, as per ethical approval. Participants were informed they had a right to access the results of the study. Therefore, participants were directed to the researcher's contact details in the explanatory statement if they wanted to request the results, also if they had any concerns in relation to the study.

4.5 Summary of Chapter Four

It is fundamental to the credibility of a study that the most appropriate research approach is selected. This chapter has provided a discussion on the evolution of grounded theory methodology and the chosen approach, constructivist grounded theory. The characteristics of the research methods and how they were applied to this study is provided, demonstrating an understanding of methodological principles. Having established the use of constructivist grounded theory to address the aim of the research, the following chapter will explore the study findings.

CHAPTER FIVE

The Research Findings

Chapter Five: The Research Findings – Understanding the phenomenon

5.1 Introduction

In the previous chapter, a detailed discussion of the methods applied throughout the research process to answer the research question was presented. This chapter presents a description of participant demographic information and the key research findings that emerged as a result of extensive data analysis. During the data collection process, participants shared rich and detailed data, based on their experiences of acute deterioration and being cared for during a medical emergency team (MET) review. The three main categories explained in this chapter are embedded within the core category and represent the actions, meanings and processes undertaken by participants in relation to their experience. As Charmaz (2014) emphasises, "the potential strength of grounded theory lies in its analytic power to theorize how meanings, actions and social structures are constructed" (p. 285). It was evident from the data that experiencing acute deterioration and MET review was multifaceted and influenced by contextual factors that participants perceived to be of significance. Although some of the responses varied and were attributed to contextual conditions, the core process is common to all participants.

In this study, the central question for individuals who participated in this study was *how do individuals construct their experiences of acute deterioration?* Although their responses varied, this problem was a shared central concern for all participants. The basic social process that patients utilised to deal with the central problem is conceptualised as (Hall et al., 2013): *Unravelling a complex experience: contextualising patients' experiences of acute deterioration and medical emergency team (MET) encounter*. This core category is common to all participants and offers an abstract interpretive understanding of the research phenomenon constructed from the data and encapsulates the resulting theory (Hall et al., 2013). The three categories discussed in this chapter: (1) *Experiencing changes – before the encounter*, (2) *Perceiving the reality – the encounter*, and (3) *Reflecting on the events – after the encounter* represent the major activities participants engaged in response to the central problem and are embedded within the core category. The contextual factors that influenced these responses included: *(i) expectations and illness perception; (ii) relationship with the MET;* and *(iii) past experiences*. In order to orientate the reader to the study in its entirety, Table 5.1 provides a visual overview of the research findings.

Table 5.1: Overview of the Research Findings

<table>
<tr><th colspan="3">CENTRAL QUESTION</th></tr>
<tr><td colspan="3">How do individuals construct their experiences of acute deterioration?</td></tr>
<tr><th colspan="3">CORE CATEGORY</th></tr>
<tr><td colspan="3">Unravelling a complex experience: Contextualising patients’ experiences of acute deterioration and medical emergency team (MET) encounter.</td></tr>
<tr><th colspan="3">CATEGORIES</th></tr>
<tr><td>Experiencing changes – before the encounter</td><td>Perceiving the reality - the encounter</td><td>Reflecting on the event – after the encounter</td></tr>
<tr><th colspan="3">SUB-CATEGORIES</th></tr>
<tr><td>Feeling something is wrong
Experiencing emotions</td><td>Something lost
Building a relationship
Developing of personas
Being in good hands
Facing death</td><td>Experiencing an impact
Seeking understanding
Accepting of events
Wanting to be seen
Advising others</td></tr>
<tr><th colspan="3">Contextual Conditions</th></tr>
<tr><td colspan="3">1. Expectations and illness perception
2. Relationship with the MET
3. Past experiences</td></tr>
</table>

5.2 Description of Participants' Demographics

In total, 27 patients participated in the study. Demographics revealed that a large portion (n=17) were women. With regards to age profile, most participants (n=21) were aged over 50 years. Regarding country of birth, 23 participants were born in Australia, with four (4) originating from China and England.

Data showed that the most common reason for a MET review was decreased blood pressure (n=15), following by increased respiratory rate (n=4), decreased Glasgow Coma Scale (n=3) and decreased heart rate (n=3). Increased temperature (n=1), low oxygen saturations (n=1), facial and throat swelling (n=1) and concern by the bedside nurse (n=1) were other reasons a MET review was activated. Classified as day 0, six (6) MET reviews occurred on the day participants presented to hospital. Whereas, over half of the MET reviews occurred between days one and five (n=15) of the participant's admission. Only three (n=3) MET reviews happened 11+ days into the participant's admission. Commonly, a MET review occurred on the medical ward (n=11), followed by the surgical ward (n=6) and emergency department (n=6). Only two (n=2) MET reviews occurred in theatre recovery with one (n=1) in critical care and one (n=1) on a rehabilitation ward. Table 5.2 provides an overview of participant demographic data.

Table 5.2: Demographic Data

Number of participants	N = 27
Gender	
Male	10
Female	17
Age (years)	
30-39	3
40-49	3
50+	21
Country of birth	
Australia	23
China	2
England	2
Reason(s) for MET review	
Decreased Glasgow Coma Scale (GCS)	3
Decreased blood pressure (BP)	15
Increased respiratory rate (RR)	4
Decreased heart rate (HR)	3
Increased temperature (Temp)	1
Low oxygen saturations (SaO2)	1
Facial and throat swelling	1
Bedside nurse was concerned	1
Day of admission the experience occurred	
0	6
1-5	15
11-19	2
20+	1
Location at time of MET	
Medical ward	11
Surgical ward	6
Emergency department	6
Critical care unit	1
Theatre recovery	2
Rehabilitation ward	1

5.3 Presentation of Findings

Although there is no prescribed way to present GT study findings, the findings should be presented in the form of categories supplemented by excerpts from the data (Birks & Mills, 2015). Charmaz (2014) suggests that findings can be presented as story or narratives that include categories told by the researcher with a focus on understanding social processes. It is imperative that the researcher's analysis tells a story about people, social processes, and situations (Hallberg, 2009). In this study, there was a clear interdependent relationship between the developed categories with the potential for factors emerging from one category to influence another category. A sequential format was chosen to present the study findings to clarify the interdependent nature of this relationship and to facilitate discussion of the categories. In this chapter, extant literature is not drawn upon to ensure participant voices are heard and to appreciate their contributions to the research. Instead of extant literature, the discussion is supported by participant quotations extracted from the data. Charmaz (2006, 2014) suggests that presenting the findings in this way provides value to research participants' narratives as well as supporting the credibility of the research. Throughout this chapter participant quotations are identified by pseudonyms.

5.4 Category One: Experiencing Changes – Before the MET Encounter

This category explores a broad range of material that focuses on the process participants experienced, beginning with their own acute deterioration. The category, *Experiencing changes – before the encounter,* is further conceptualised through two sub-categories: *Feeling something is wrong* and *Experiencing emotions.* In the beginning, most participants recognised the onset of their own acute deterioration: *Feeling something is wrong.* For many, this insight and understanding triggered a response such as fear and anxiety: *Experiencing emotions.* For all participants, a combination of physical and psychological changes resulted in a MET review: *Perceiving the reality.* It is important to point out that not all sub-categories were pertinent to each participant. Participants varied both in terms of how many of the sub-categories were relevant to their particular situation and the importance placed on each of them. Data analysis uncovered that experiencing acute deterioration is unique, extensive and complex. For many, experiencing acute deterioration and a medical emergency team (MET) encounter was the most clinically intense part of their hospitalisation.

5.4.1 Feeling Something is Wrong: Recognising Acute Deterioration

From the perspectives of the participants, many recognised their own symptoms of acute deterioration and these were found to be a central trigger that escalated their care. The term 'feeling' is defined by the Macquarie Dictionary (2019) as 'experiencing a sensation.' In this study, various terms were used by participants to qualify 'feeling something is wrong.' Commonly, participants used terms such as *'not feeling well', 'feeling terrible', 'sick', 'flat', 'wasn't in a good place' and 'feeling worse.'* Most participants, to some degree during their acute deterioration, were involved in the process of feeling something was wrong. This process involved interpreting physical signals and assessing their severity.

5.4.1.1 Interpreting Symptoms and Evaluating Their Severity

Many participants, during their acute deterioration, were involved in the process of interpreting their own symptoms that warned them of a potential danger. Many participants described feeling *'pain', 'nausea', 'aches', 'breathless', 'hot', 'cold', 'clammy', and 'dizzy'*. For example, Angela experienced three MET reviews in the space of 24 hours. Prior to her first MET encounter, she experienced unusual physical sensations, notably intense pain, nausea and shortness of breath. Angela interpreted these atypical physical symptoms as a warning that something was wrong which caused her to worry and seek help from her bed side nurse . Angela explained:

> *I'd been on antiemetics and pain relief, I think I'd just been asleep. I woke up and the antiemetics had worn off and the pain relief had worn off, and I was just like shocked. Not with it, crying, in a lot of pain and not being able to breathe properly.*

Amber's experience of acute deterioration was similar to Angela's encounter. Amber was about to be discharged from hospital before being told she would need to stay due to "*funny blood test*" results. Soon after, Amber began experiencing atypical symptoms which caused her to seek help from her bedside nurse. Amber's MET encounter resulted directly from her interpretation of physical symptoms. She said, "*I started to get quite a bit of pain in my side, feeling very unwell…I can remember screaming in pain and then hearing MET review."*

Participants experiencing acute exacerbation of a chronic condition did not experience a sudden warning as such, instead their deteriorating symptoms became the catalyst for knowing something was seriously wrong. For example, George had experienced symptoms associated with heart disease for 20 years; it was only when his blood pressure dropped his symptoms became worse. The worsening of his symptoms, and the added symptom of breathlessness, caused George to recognise his own acute deterioration. As he explained, "*I was very aware when my blood pressure dropped that I wasn't in a good place, wasn't scary but I knew I wasn't in a good position."* For Alex, it was not the exacerbation of her symptoms that played a role in recognising her own acute deterioration, but the fact her symptoms had not improved from a particular treatment. Only when this occurred, Alex considered it necessary to address her deteriorating condition by presenting to hospital. Alex explained, "*I just, I woke up and I couldn't breathe…I knew once I got here I'd be helped because they couldn't do anymore for me at home."* For Alex, the decision to present to hospital involved the realisation that her current treatment was not alleviating her symptoms and the likelihood her condition would further deteriorate. Several participant discussed being at a crossroads when interpreting and evaluating their own physical symptoms, now knowing if their discomfort was worth seeking help from their bedside nurse or calling an ambulance. For example, Henry found it difficult, while as an inpatient, to interpret his deteriorating condition and call for help:

> *Henry: The nurse said, "You're not looking real crash hot". After around about half one I couldn't get back to sleep and realised that my breathing was getting much shallower and very crackly*
>
> *Interviewer: Did you press your hospital call bell to inform your nurse?*
>
> *Henry: No, I waited for the nurse to come back and check on me which was about 3.30.*

Henry was aware of the nurse's initial observations of his condition and therefore expected her to return if she felt he needed further assistance.

For those who had experienced acute deterioration before or an acute exacerbation of their chronic condition, symptom analysis was simpler because they had prior experiences and knew when to initiate a call for help. For example, having lived with respiratory illness for many years and having experienced a MET encounter during a past hospital admission, Joan knew that if she did not take her medication at a certain time of day it would affect her breathing and cause an acute exacerbation of her chronic condition. She explained, "*I was getting a bit jittery, because I knew I wasn't going to be getting any medication, proper medication…thought well this is the result of what that has caused."* Interpreting physical symptoms and evaluating their severity differed for each participant. Because they lived with their illnesses and are familiar with the associated symptom, participants diagnosed with chronic conditions become rather proficient with symptom analysis compared to others. A number of participants acknowledged that they did not understand the severity of their acute deterioration but typically knew that they were unwell and required treatment. Kelly, for example, recalled being unwell but at the time did not realise how clinically unstable she was. Kelly explained:

> *I felt a bit flat. I was a little dizzy but thought that was because of the morphine…I didn't think anything of it. It was just when they did my obs [vital signs observations], they realised that my blood pressure was really, really low.*

This was a similar path for George as, on reflection, he did not realise how unwell he was at the, "*I started to realise only after I started to improve how unwell I was, I didn't realise at the time."*

5.4.2 Experiencing Emotions

This sub-category relates to the thoughts, feelings and perceptions participants had regarding their acute deterioration. For some, this array of emotions went beyond those experienced in everyday life, making it difficult for them to understand. It was through these emotions that participants construed various aspects of their experience. Participants then reacted to various stimuli in their environment depending on their response. Therefore, depending on the emotional response a participant had, it influenced their experience within other categories. Consequently, participants' experiences of acute deterioration differed. It must be noted here that individuals' personalities, as well as previous experiences of acute deterioration, also influenced how they interpreted stimuli through any psychological frame. Thus, personal experiences were not just compromised of thoughts, feelings and perceptions individuals had regarding the nature of their acute deterioration, but also of the various characteristic and past experiences they may have had. The following responses were delineated by participants when feeling something was wrong, fear and anxiety.

5.4.2.1 Experiencing Fear and Anxiety

Experiencing fear and anxiety in response to the physical symptoms of acute deterioration was commonly discussed by participants in this study. In this study, the term, 'fear' is defined as "an emotional response to perceived imminent threat or danger." (American Psychiatric Association [APA], 2013, p. 821). Whereas 'anxiety' is defined as "the apprehensive anticipation of future danger or misfortune accompanied by a feeling of worry, distress, and/or somatic symptoms of tension. The focus of anticipated danger may be internal or external" (APA, 2013, p. 818). Participants experienced fear and anxiety in varying degrees and this was dependent on how they interpreted the severity of their physical signs, and in some cases their external environment. For example, Terry presented to the Emergency Department (ED) because he was having difficulty breathing and feeling generally unwell. He not only feared the symptoms he was experiencing, but he also felt anxious because of where he was placed within the ED: *"I was feeling so terrible, I couldn't breathe and I had pain everywhere. I was scared and feeling anxious, until they put me in another bay before taking me to ICU."* When Terry was initially admitted into ED he was placed in a resuscitation bay which caused him further anxiety. Although this was his first time being in a resuscitation bay, on previous presentations Terry had witnessed "*seriously ill patients taken in there*." Therefore, he associated the seriousness of his condition by his location in the ED and it was only when he was moved from this location and his physical symptoms improved that his anxiety subsided.

A number of participants identified that fear and anxiety had a substantial impact on their experience of acute deterioration. Alex, said *"…When you can't breathe it's the most frightening thing…I was panicking so much."* Sam also discussed the impact fear and anxiety had on him *"I've never experienced this feeling ever before. It was horrific. It was so scary."* He qualified this by explaining that this feeling would remain with him, "*It's just something…I knew the way I felt, that I was finished…The feeling's going to be with me forever…I've experienced nothing like it before. It was scary and horrifying."*

One participant, Tim, associated fear and anxiety with losing control during his acute deterioration. Tim experienced an anaphylactic reaction which caused sudden swelling to his face and tongue as well as difficulty breathing: *"I was no longer in control of what was happening to me."* Tim further qualified this by explaining, "*My face was swollen so I couldn't open my eyes properly…I had trouble breathing…It's actually a very bad experience because you feel like you are not yourself anymore…it was quite frightening because I lost control."*

Fear and anxiety was also found to have developed when a participant's acute deterioration was unexpected. For example, Kelly's condition became unstable due to low blood pressure, she initially was not concerned as she associated the dizziness she was experiencing to the analgesia she had received prior. Before staff escalated Kelly's care to a MET review, she overheard a doctor discussing her potential transfer to ICU, which intensified her experience of fear and anxiety. Kelly stated: *"Emotionally, I was a little worried but especially when they said they were going to take me to ICU. Obviously I knew it was a bit more severe than what I thought it was."* As Kelly was expecting to undergo a simple procedure without any complications, she also had feelings of uncertainty: *"I was a bit scared and uncertain about what was going to happen. Quite shocked because I was coming in for a simple procedure."*

In contrast, two participants interviewed were explicit in their descriptions of not experiencing fear or anxiety as a result of their acute deterioration. George explained that his physical symptoms did not scare him as he was not afraid of death, saying: *"I wasn't scared when my blood pressure dropped, death doesn't worry me. So, it didn't scare me."* George further explained that his previous experience as an inpatient in the hospital was also a factor: *"Just the fact that I was in the right place and I just think that the hospital has been good to me. I think they have done everything right and I just accepted that I was in the right place."*

Mary also did not experience fear or anxiety during her acute deterioration. Her physical symptoms consisted of right-sided weakness, a headache and some vision loss. Mary's daughter took her to the ED where she was assessed for a possible stroke. Mary was aware of the potential cause of her symptoms but was not concerned, she said: *"Didn't worry me…nup, I was too crook to be scared."*

5.5 Category Two: Perceiving the Reality – The Encounter

The term 'perceiving the reality' refers to a person's experience, including emotions, thoughts, and sensations, which move through a lens of their conditioning, therefore creating their perception of the world. In a constructivist grounded theory study, 'reality' is seen as dynamic, and that individuals construct local meaning about reality to understand and act on it within their immediate context (Charmaz, 2014; Fiori et al., 2017). Therefore, there is always a possibility of multiple and even competing perspectives of the phenomenon in a highly complex social world (Fiori et al., 2017). In this study, each participant shared their own reality within the highly complex world of acute deterioration and a MET encounter. Therefore, this category reflects the participants' perceptions of reality within the context of a MET review. The category *Perceiving the Reality – the encounter* is further conceptualised through five sub-categories: *something lost*, *building a relationship; developing of personas; being in good hands; and facing death.* Participants who had a previous experience of being cared for during a MET review had been exposed to this 'reality' before. This familiarity had an effect on how they interpreted their experience. In the following presentation, each sub-category of *'Perceiving the reality – the encounter'* will be discussed with an emphasis on how the experiences represented by these sub-categories were different for different participants.

5.5.1 Something Lost

Participants recollections varied from no memories to vivid recall of events. Some participants had no recall of their MET encounter: "*I don't know what happened, I really can't remember a lot of what went on."* (Tara)*; "I can remember screaming in pain and then I don't remember anything else."* (Amber)*; "I don't have any recollection from the time everyone came in."* (George)*; "I can't really remember anything."* (Paula)*; "I don't really remember much."* [Jill]*; and "I* *don't remember much about the code".* (Wendy). One participant noted*: "I can't remember…just hearing them talking and maybe asking me if I knew what happened but I can't fully remember."* (Heather). Although some participants had limited or no recall of their MET encounter, what they did recall was of significance to them. For example, Heather first stated that she could not remember what happened but when allowed time to reflect she recalled: *"feeling not good and dizzy, dry in the mouth"* before waking to maybe *"6 or 7"* healthcare professionals looking over her. She remembers *"the lady from across the room came to help me, she was lovely, she's been sick herself. I think maybe she called them (MET)."* This was similar for Paula who first identified that she could not remember her MET review. When given an opportunity to reflect on the events she recalled *"I couldn't keep my eyes open. They (MET) were just making sure I was conscious and just going through their processes…they were getting the paddles organised"* and *"I felt nauseous and cold."*

Others had some recall but were concerned by the loss of time they experienced. For example, Beth was "worried" by the limited recall she had of the events leading up and during her MET encounter, Beth explained: "*It feels like you have lost time in your life…it's like you are in a vortex and you have lost something."* She qualified this by explaining:

> *You have lost time that you will never get back, you want reassurance that everything is okay…once everyone disperses you think about it afterwards and wonder, what happened?...You tend to query yourself, like what happened? But no one is there to answer, it's just part of it. So, I don't know, whether ward staff can answer that, I don't know.*

The most significant aspect of Beth's experience of a MET encounter was the loss of time. Beth summarised this by explaining: *"I think the biggest thing is the loss of time and you can't get that back. Because that's never going to reveal itself is it? So, you just put it down to that's part of life."*

Some participants, such as Tim and Rose, acknowledged the importance of control in managing their acute deterioration and MET encounter. For example, during Tim's MET encounter, losing control had a significant meaning for him. He recognised that he was no longer in control of his emotions and what was happening to him, which he described as frightening and overwhelming, "*It was quite a frightening experience because you lose control. You are no longer in control of what is happening physically and emotionally. Although there was a number of people there at the time to help, it's overwhelming."* For Rose, losing control was associated with her physical and emotional wellbeing at the time of the MET encounter and the outcome of her acute deterioration. Rose said: *"You know it was very wearing. It's a threatening situation…you are not in control."* Rose qualified this by explaining that she did not have any control over the outcome of her acute deterioration, this control was now with the MET, but she knew she was in good hands: "*You are not in control and don't know if you will come out the other side… I felt quite safe in their hands…I told myself 'lay back and relax, there's nothing you can do about it."*

5.5.2 Building a Relationship

From the perspectives of the study participants, the relationship they had with members of the MET was found to be a central influence on their experience. The term 'relationship' is defined as a connection or emotional connection between people (Macquarie Dictionary, 2019). The healthcare professional – patient relationship has been described as an essential component to patient care and is based on trust and respect (Griffith, 2013). Numerous terms were used in this study to qualify the type of relationship participants had with members of the MET. For example, participants used terms such as *'trusting', 'safe', 'good'* and *'respectful'* when they valued a particular connection they had with members of their MET. Relationships have been described different in this study and participants suggested that their levels of coping, comfort and satisfaction was reliant on the relationship formed with members of the MET who were responsible for their care. On reflection, the relationships participants formed with their MET ranged from simple descriptive encounters to deeper reflections that represented more personal meanings, which influenced their experiences. Although participants recognised that failure to develop a relationship with MET members rarely occurred, some situations were discussed where participants were conflicted by the type of relationship they wanted with their MET. For example, Amber identified that her experience with the MET was "alright" but she discussed wanting more from the team, such as therapeutic touch: *"to be a bit tactile…just a hand on the shoulder*." The factors that were vital to participants' relationships with the MET included: *the demeanour of the MET; and the focus of the MET*. Both are discussed in detail below.

5.5.2.1 The Demeanour of the MET

As defined in the Cambridge Dictionary (2020), 'demeanour' refers to a way of looking and behaving or the outward behaviour or bearing. In this study, 'demeanour' refers to the ways the MET approached and behaved towards the participants. From the perspectives of the participants, the demeanour in which they were approached was found to be a central influence on their experience. When participants were satisfied or had a positive experience, they discussed a particular approach or demeanour by members of the MET. This demeanour was described as '*professional*', '*efficient*', '*calming*', '*reassuring*', '*considerate*', '*compassionate*', '*kind*', '*respectful*', '*supportive*', '*helpful*', and '*thorough*' which made participants feel safe and confident. However, when participants had a negative experience they described a different demeanour or approach which made them feel excluded or distanced from members of the MET which caused uncertainty and fear.

A number of participants identified members of the MET who they had valued during their review. Sarah's bedside nurse initiated her MET review as Sarah was experiencing a warm, clammy feeling, swelling to her tongue and high blood pressure. During a highly stressful situation she said: *"The experience was made a whole lot easier because of the nurse…she was there to make sure people weren't going too far…she was marvellous absolutely marvellous"*. Sarah qualified this by explaining the nurse went beyond what she expected her do:

> *The nurse was being very forceful in what she was saying about my blood pressure being so high, she was making sure because she felt the doctor wasn't taking that into consideration. I know she reiterated that several times…I was grateful that she was doing that. I knew she was on my side. I don't know what I would have done without her. I really don't.*

In the first instance, Alex also described the demeanour in which the MET approached her as marvellous: *"they were absolutely marvellous…I couldn't complain about them whatsoever".*

Being 'marvellous' offered a possible explanation of a range of behaviours by the MET, but participants often struggled to interpret and describe its meaning. When referring to 'marvellous', Alex talked about the MET members being kind, considerate and compassionate which she valued: *"I just thought how marvellous they were. I know I am dying so, they were kind, consideration and compassionate. Couldn't have asked for anything nicer at the time."* Rose explained marvellous as the MET not 'messing around' and 'having her best interests in mind', she explained:

> *I thought they were marvellous, I wasn't up to doing anything much and they just took over, and I felt quite safe in their hands…they don't mess around, they've got your welfare at the back of their minds. You know, what's not to like about that?*

Joan referred to marvellous as *"a beautifully structured team".* She qualified this by explaining, "*Just how the team came in, all of them you know there were so many, but each one was verifying for the others and somebody else and things were being done, it was marvellous to see."*

The first meeting between patients and members of the MET was found to have an impact on participants' experiences. Throughout the findings, participants described their first meetings with members of the MET in varying degrees. One participant, David, described his first experience as a hospital inpatient that resulted in a MET review: *"This is my first time in hospital so when I see a lot of doctors around me…about six or seven people…I just think, what is going on with me, I don't know what has gone wrong".* The presence of the MET caused David to worry about his health and this concern continued throughout his hospital stay. In his first meeting with the MET, James also discussed the number of health care professionals present: *"I was feeling pretty hot and the next thing I look around and there's people all over me…maybe eight people…they just attacked me."*

Both David and James discussed feeling overwhelmed by the number of healthcare professionals who presented as part of the MET. James believed that the feeling of being overwhelmed was due to being 'attacked' by the MET. A number of participants interviewed also described feeling '*attacked*', '*surrounded*' or '*invaded*' by the MET. Amber recalls being in radiology for an ultrasound when her condition suddenly deteriorated and a MET review was initiated, she recalls screaming in pain before hearing 'MET call', and then became unconscious. Amber's first memory was being back on the ward where her first meeting with the MET occurred, she explained: *"I came to and I was surrounded by about 15 people, wondering what was going on…"* One participant interviewed described the MET's initial approach involved no introductions or explanation before treatment began (Henry). Henry linked the manner of the MET to him feeling invaded, he explained:

> *No one really talked to me…In normal circumstances, you would have to say physically you feel invaded. But I was feeling so ill that I left myself completely open to the mechanics and said, 'well whatever is going to be is going to be.'*

In contrast, some participants described feeling overwhelmed by the MET's approach, but their demeanour was reassuring. Tim explained: "*Although there was a number of people there at the time and I felt a bit overwhelmed, I also felt reassured*." He qualified this by explaining: "*They conducted themselves in a very professional, calm manner. Especially one nurse, she gave thorough explanations as to what was going on and why this was happening to my body."* Alex also discussed feeling frightened by the MET's initial approach, but their demeanour was reassuring: "*When you can't breathe it's the most frightening thing and they just calmed me down…they reassured me and told me what was going to happen…*"

Many participants interviewed acknowledged the importance of the MET initial approach to the development of a connection. Margaret described how she tried to engage members of the MET in conversation by asking "*how are you*?" and pointing out "*gees there's a lot of you*" in an attempt to develop a connection with the team. She had little success and instead listened to their conversation. Margaret had some medical knowledge and from what she overheard she thought: "*this doesn't sound good*". Instead of the MET "barging in" which caused her to feel overwhelmed, Margaret suggested in the first instance a "spokesperson" from the MET should have built a connection with her, explaining:

> *Well, if they had of come in and had one spokesperson say um 'Hi Margaret…apparently you have come up from radiology and a couple of stats the nurse have done while you were there, were either too high or too low and because of that it has automatically kicked us into care. We are known as the Medical Emergency Team, we are here to double check in a hurry everything is okay...this is your whole big protection and we are going to get everything done here and make it extra supportive.' So, if they had said that I would have gone, 'go for it guys, go on and I thought thank god for that.' But when they sort of all came in and they were caught up in their stuff…*

Ultimately, the demeanour of the MET caused Margaret to experience fear and uncertainty, which she believed could have been avoided.

A number of patients questioned the seriousness of their condition by the number of healthcare professionals present. Julie explained: *"something was going on, I knew something was badly wrong with me for so many people to be in the room."* Alex compared her MET encounter with previous experiences of being cared for in hospital: "*usually when I come there's a couple of people but this time I reckon there was eight or ten people."* Initially, Anna did not realise she was in danger. It was not until many health professionals presented as part of the MET that she realised the seriousness of her condition, Anna explained:

> *I didn't know I was in any danger for a start. All of a sudden, one nurse was there putting my bed down, so I thought something was not right. Next thing they had doctors and nurses from everywhere and I started to put it together.*

Tim also interpreted the seriousness of his condition and thought he was in trouble based on the number of healthcare professionals present during his MET encounter, he explained: "*It's still a bit scary. The number of doctors I had means I'm in trouble, if I have one or two, okay that'll be fine. But maybe it was like five or six nurses and doctors."*

During his MET encounter, Daniel, not only associated the seriousness of his conditions to the number of healthcare professionals present, but also described the MET's approach as being like "flies." He explained: *"I didn't know what was going on. This one coming in. It was just like flies coming in and another one and another one. Full up. I thought it was something going haywire."* This was a similar interpretation to Mary, who also described her MET's approach as being like "flies." She said: "*All these doctors come zooming in like flies…there would have been at least six I reckon."*

Some participants associated the approach of the MET to what they had seen on television.

Margaret explained:

> *They are taking blood, they are putting stuff in and they are taking temperatures, they are taking pulses, they're taking everything I have. To the point where part of me was looking around for the TV cameras, I was just about ready to crack up laughing, because I thought I watched this on you know, Diagnosis Murder*.

Similarly, June compared the MET approach to something out of a movie:

> *…one of the nurses just hit the buzzer and everyone came in here. It was like out of the movies…Doctors over there reading my history, nurses doing all sorts of things. I even had a girl taking blood or something out of me.*

When participants did not have positive MET encounter experiences, commonly it was due to the demeanour of the MET. Jessie identified one nurse (her bedside nurse) who she had not wanted to be involved in her care during her MET encounter, and described him as uncaring and grumpy. Jessie thought he had abandoned any attempt to reassure her when she experienced acute deterioration in the lead up to her MET encounter. Jessie summarised her thoughts towards this nurse: *"…he didn't have compassion, kindness or manners."* Participants were inclined to assess demeanour in the early stage of their relationship with the MET and this had an impact on their experience. Although Amber's experience of the MET was not entirely positive due to the team's demeanour, she did appreciate that they saved her life. She explained: "*They are more interested in trying to save your life than explain what they were doing…I am grateful I am still here*."

Although some participants would make the judgement that the MET lacked the ability to reassure them due to their initial approach or demeanour, they did not allow that judgement to influence their experience. One participant described the MET's "clinical" approach and how he tolerated the MET's lack of reassurance, because of their expertise:

> *I was feeling so terrible, I couldn't breathe and I had pain everywhere. I was scared…they didn't reassure me…they were talking and chatting and doing everything all around me, like putting in needles…they didn't speak directly to me, it was very clinical…I told them I thought that was the end, I said 'you must have worked well to get me back.'* (Terry)

5.5.2.2 Engaging with the MET

Participants perceived they were central to the MET's concern when they were focused on as individuals. Participants measured the healthcare professionals' level of interest in and focus on them by their use of communication, touch, supportive manner, and reassurance. For example, Tim believed his MET cared for him because of their supportive approach. He said:

> *If you've got somebody that's also giving that emotional support then it aids in recovery and the whole experience. Maybe I was quite fortunate to get a really good team…they were really quick. They were efficient. They were thorough and they were emotionally supportive.*

Communication often had a positive meaning for participants and was associated with safety, trust and confidence. During his MET encounter, Tim felt safe with the team because of how they interacted with him. His speech was impaired and the MET's approach to communication was simple and direct, he explained:

> *It was very simple. They didn't overcomplicate the experience and they didn't obviously because my speech was impaired. They didn't overload me trying to get too much information. So, it was very short and simple and direct. And they got the information that they needed in a very, very short time with understanding my capacity to be able to answer.*

For Paula, a positive experience of communication had a significant meaning. Paula described it as: *"very good during a stressful time…the way they spoke to me, making sure I was alright over and over again"*. The trust and confidence Paula had for the MET was built from communication: *"they kept me well informed of what was going on with everything. Every question I asked was answered. They explained to me anything I wasn't sure of… they explained to me, they didn't want to take any chances with me, so I was to go to CCU."* Not only did Paula have a positive experience during her MET encounter but also after her condition was stabilised. She explained:

> *They stayed with me for half an hour or so afterwards to make sure I was okay. They talked to me, reassured me and all that. They also had a few jokes that made me feel better. I couldn't have asked them to do anymore, really.*

In contrast, negative experiences of communication with the MET were found to be associated with emotions such as frustration, vulnerability and fear, and a sense of ill ease at not being treated as a human being. Some participants reported feelings of frustration and being powerless due to their decreased ability to communicate. For example, Sarah was frustrated that she could not articulate how she was feeling to the MET due to swelling of her tongue: *"I was trying to make myself understood and feeling frustrated because normally I can speak properly."* In response to Sarah's inability to communicate effectively, members of the MET began "poking" at her: *"one of them in particular, was really over the top prodding and poking at me…shooting, firing* *questions at me and I was pretty slow in my thinking and couldn't articulate…it was pretty annoying."* In this situation the MET attempted to conduct their medical assessment by touching Sarah roughly and they stopped any attempts to communicate with her. Their lack of impersonal touch and communication failed to recognise and acknowledge Sarah a person, causing her to panic.

A number of participants talked about not being able to understand what was being said to them by members of the MET. A participant talked about feeling secure by the physical presence of the MET but scared at not being able to understand what was being said: *"I think there were talking a lot together themselves because I couldn't understand half of what they explained to me…I'd just sit there and say nothing"* (Sam). Sam also indicated that medical and nursing staff did not clarify his understanding which caused him concern: *"…sort of worried, I've got this feeling because this is my second MET call in three years and I don't understand what happened."* Henry also indicated that he did not completely understand what the MET was saying to him: *"I had no idea and they probably wouldn't explain it to me anyway, after all I am only the patient."* Sarah, Sam and Henry were all left with feelings of being passive participants and taken over by others, which they all described as overwhelming and frightening. Henry summarised: *"I feel like I'm dying and no one has told me."*

Commonly, participants characterised their MET as good and bad. All participants noted that competency and personality of MET members influenced their perception of a good or bad MET encounter. Participants used a variety of descriptors were used to characterise a 'good' MET: '*knowledgeable*', '*good*', '*were there is a hurry*', '*efficient*', '*provided comfort and reassuring*', and '*took the time to explain*.' The characteristics of a 'bad' MET included: '*detached*', '*rushed*', '*delayed in arriving*', '*disorganised*', and '*did not explain*.' Interestingly, many participants placed importance on therapeutic communication rather than clinical competence. Joan described the MET as being: *"a beautifully structured team"* that *"even if you think you are on your last breath, you think thank God you are in really good hands."* But for Joan this was not enough, she recalled the MET being: *"caught up in their stuff"* which caused her to be scared and overwhelmed.

As discussed by participants, the qualities of a 'good' MET related to providing good care in a hurry, providing comfort, support and reassurance, being an advocate for the patient, keeping the participant informed, showing compassion and being empathetic, and being efficient. For Kelly, the MET demonstrated many of these qualities and it made her feel secure. Kelly described a 'good' MET as efficient, keeping her informed, working as a team, and demonstrating clear and concise communication between them. Kelly explained:

> *They were really good, they were explaining to me what they were going to do…the entire team was communicating with me and then they would communicate with each other,*

> *everyone knew what was happening…I was quite shocked because I was coming in for a small procedure but I felt secure because of how quickly they came to help me.*

This was a common theme amongst participants when experiencing a 'good' MET. Participants felt they were better able to cope with their illness and influx of emotions associated with a MET encounter because of the support they received from MET members.

The characteristics of a 'bad' MET or negative experience, as explained by participants, related to being disorganised, not attending the participant in a timely manner, losing sight of the person in the bed, not being attuned to the patient's needs, poor communication, not being informed and causing the participant pain. Angela described her negative experience with the MET as bizarre, qualifying this by explaining that the MET was disorganised and did not pay her attention:

> *It was really bizarre because more and more people kept rocking up and I was having to repeat the same thing, I was in so much pain and they kept asking me the same questions over and over…I kind of felt like they talked down to me and they were disorganised…They were so busy talking about me they didn't pay attention to me, like when I was throwing up, I just wanted a tissue to wipe my mouth…You're definitely a number.*

Sarah and Tara both experienced acute deterioration and MET encounter due to a medication error, administered by a healthcare professional. Both Sarah and Tara had negative experiences with their respective METs, relating to pain. Tara said, *"It was hurting my arm. I kept saying, 'Please don't do it anymore', but they kept on doing it…I suppose they had to but I didn't want them to touch me."* Sarah also explained:

> *You can't do that. You're hurting me, you're hurting me. You have to take it out! I want you to take it out! He took it out and comes at me with another one and he says, 'I have to put another on in'. I said, 'Do not come near me'.*

For some participants, a negative experience had a lasting effect. It caused a spectrum of feelings such as worry, helplessness, hopelessness and vulnerability. For example, as a hospital inpatient, Julie recognised her own acute deterioration and assessed the symptoms she was experiencing as *"something was badly wrong."* She called for help but noted it took *"so long for them (MET) to get here"* which for Julie was *"the frightening part."* Julie perceived this delay in receiving assistance from the MET negatively which had an impact on the remained of her hospital stay. Daniel had a similar experience to Julie when he was waiting for the MET to arrive, he said, *"I was waiting and waiting and waiting and no one had come."* A negative experience with the MET also caused participants to worry about their health and be concerned about further episodes of acute deterioration and interaction with a MET. Tara expressed worry and concern that influenced the remainder of her hospital admission. She explained:

> *I was frightened it would happen again and it made me question everything…I'd keep apologising, saying to the nurses, 'Look it's not you. It's just that I've had that bad experience'. I had to keep finding out what they were giving me, why and how much.*

5.5.3 Developing of Personas

The term 'persona' refers to a mask or shield which a person places between themselves and the people around them to conceal their true nature (Perlman, 2018). Ricci (1997) refers to a patient persona as "the social self the patient appears to be to others as opposed to the individual's real or true self" (p. 131). Ricci (1997) explored the patient's hospital experience and identifies three patient personas: consumer, recipient and non-patient. In this study consumer and recipient persona is used to explain the different personas or masks participants assumed while being cared for during a MET encounter. From discussions with participants, the difference between the two personas involved being assigned the role by the MET (recipient) or choosing their role (consumer). Commonly, participants moved between personas which was influenced by contextual conditions (e.g., expectations and illness perception, a previous experience of acute deterioration and MET encounter and previous hospital admissions).

5.5.3.1 Recipient Persona

Most commonly, the recipient persona was adopted by participants during their MET encounter. The term 'recipient' is used to describe a passive individual waiting to receive treatment, rarely being involved in the decision making process (Henderson, 2003). It also suggests a power imbalance between the patient and healthcare professional providing care (Costa et al., 2019). As discussed by participants, the characteristics of the recipient persona included the following terms: "*do not interfere*" (Henry and James), "*passive*" (Rose, June, Sam and Julie), "*loss of control*" (Rose and Tim), "*did not ask questions*" (Daniel, James and Sam), "*compliant*" (Sarah, Anna and Alex), "*did not complain*" (Angela) and "*dependent*" (Jill and Sarah). Participants acknowledged it was important that patients did not interfere with the MET and decisions made about their treatment. Henry, for example was asked what advice he would give to patients who may be cared for by a MET. He said: *"sit back and enjoy the show, let the professionals do what they know best how to do, without interference. You are just the body in the bed."* This was a persona also recommended by James: *"they've got a job to do. You can't interfere. You can't tell them what to do or how to do it or when to do it, they all know what they've got to do."* Along with advising patients not to interfere with the MET, many participants suggested this persona to ensure the MET review ran smoothly: *"Relax and know what they're doing is to help you. Not to hurt or harm you in anyway. It's just to make it as smooth as possible."* (June).

When participants discussed the persona, they adopted during their MET encounter, there was some commonality. Participants who typically describe themselves as passive or laid back were more inclined to embrace the characteristics of the recipient persona. For example, when not in hospital, George described himself as accepting, passive and optimistic. During his adult life, George had endured many hospital admissions and procedures to save his life, during which he maintained this passive, compliant and optimistic style via adoption of the recipient persona, he explained:

> *When you've been in my situation, some 28 years ago I had open heart surgery for a triple bypass…it was a big deal in those days and I knew there was a chance I wouldn't come out of it, I understood and accepted it…I have a strong commitment to live which I believe is like positive thinking.*

Interestingly, individuals who experienced acute deterioration and MET encounter for the first time were less likely to adopt a recipient persona than those with an acute exacerbation of chronic conditions and had experienced a MET encounter before. Alex, for example, had been hospitalised many times and was familiar with the hospital setting, medical procedures and MET reviews. Therefore, during her MET encounter she tended to adopt many of the characteristics of the recipient persona: *"I just listened to them and did what they told me to do, they know what they are doing."* Likewise, Anna had experienced a MET encounter before which led her to adopt several characteristics of the recipient persona, even though these characteristics were different to her usual persona. Anna said: "*I don't usually do as I'm told but when things like this happen, I followed their lead."*

During their experience, participants recognised there were certain times during their MET encounter that forced them to adopt characteristic of the recipient persona because they did not have the strength to choose the consumer persona. Commonly these situation occurred when participants experienced symptoms such as shortness of breath, fatigue, weakness and pain: *"I suppose I kind of felt spoken down to, but then I wasn't in a fit state, I was exhausted and in so much pain."* (Sam). Beth also said:

> *There are a lot of people around you and you have to be guided by them. It's not overbearing, not intimidating…you've just got to be guided by them because they are the*

> *professionals, you can't fight it. You might not want to but it's a process, you have to go through it.* (Beth).

5.5.3.2 Consumer Persona

In health care, the term 'consumer' can be used to describe a person who chooses to be involved in the decision making process about their care (Gregory, 2007). It also implies a greater equality between the patient and health care professional providing care (Costa et al., 2019). As discussed by participants, the characteristics of the consumer persona they adopted during their MET encounter included the following descriptors: assertive, confident, taking an active role, being involved, seeking information, being equal, advocate, in charge and in control.

> *I'm not really good at all at being upfront about my care. I'll just sort of tend to sit back and whatever. But I just… I think that MET call woke me up a bit too that I have to be responsible for my care as well. It has to be like I have to be involved in it*. (Sarah).

From discussions with participant, the most common characteristics of the consumer persona were being assertive, seeking information and taking an active role. When participants were asked if they had any advice for patients who may experience a MET encounter, they reflected on what they had learnt from their encounter. David, for example, had not been hospitalised before his suspected malaria. He was unfamiliar with medical procedures, the hospital setting and a MET review, therefore, he tended to be more assertive with the MET by asking questions and wanting to understand what was happening to him. He advised patients to continue to ask the MET questions until they understand the answers and what is happening. He qualified this by explaining that a person's health is too important, and patients must understand what is happening to their body: *"If I don't understand, I always ask them again until I understand the answer…remember that your body may be sick but your brain is not."*

During a MET encounter participants adopted characteristics of the consumer persona in several ways. Participants who were generally more assertive and confident in their normal lives were more likely to adopt the consumer persona then others due to these characteristics already being part of their personality. Margaret, for example, who was usually confident and assertive believed she needed to use these characteristics during her MET encounter. She explained:

> *I felt like I needed to ask questions and find out what they were doing. If I didn't, I knew I wasn't going to be told anything. When they don't tell you anything it makes you feel like a number in the bed instead of a person.*

Whereas for Trudy, being assertive and confident was a result of having many interactions with healthcare professionals along her illness journey. Subsequently, she projected characteristics of the consumer persona during her MET encounter, to ensure members of the MET had the vital information they needed to treat her unstable condition. Trudy commented:

> *There were two doctors and they're asking all these questions at the same time and I just thought, 'I can't talk to two people at once'…I said, 'I'll try and answer your questions to the best of my ability but I can only speak to one person at a time.' So, they took a step back and took time to talk to me.*

Participants recognised that there were some situations that caused them to adopt the consumer persona over the recipient persona. Anna, for example, was hesitant to engage in certain consumer behaviours when she experienced her first and second MET encounter, however she did so voluntarily during her third MET encounter. Other participants who had experienced multiple MET encounters suggested similar. For example, Sarah displayed characteristics of the consumer persona by being assertive and active during her second MET encounter. During her first MET encounter however, she experienced a sudden onset of physical symptoms and fear that she was unable to adopt characteristics of the consumer persona in order to communicate her needs, recalling:

> *This is my second one (MET review). I had one while I was in intensive care. They gave me medication I was allergic to. So, I don't know why I was given it. I didn't think to ask about that. I just kind of assumed that my care would be taken care of while I was in intensive care.*

During her second MET encounter, Tara who was usually passive, became assertive and voiced her anger and concerns when she believed her body was being invaded. She explained:

> *One nurse punctured all of my arm trying to get blood. She said, 'I can't get any blood.' I said, 'well for God's sake leave it,' because I was getting irritated. Which I suppose nurses don't need to hear. But it's my body and I was getting a bit sort of agro [aggressive].*

Also, some participants embraced characteristics of the consumer persona when it came to decisions about their treatment. This assisted them to effectively communicate their needs with members of the MET. For example, Angela who was naturally passive, felt the need to voice her concerns to ensure the MET were aware of her wishes:

> *My blood pressure dropped to 80 [bpm] and I don't think they realised so I told them, 'I'm a do not resuscitate'…and then the doctor sent a few of them while he talked to me…They gave*

> *me blood and bought me around here to a private room…I think that was more in case I died that night.*

If participants had a prior negative experience with either healthcare professionals, a procedure or a MET they believed it was essential to adopt the consumer persona and be in charge of their own destiny:

> *He (the nurse) only did one (one rotation when cleaning the hub of the PICC) and I questioned him. I said, 'I think you're supposed to do at least two times.' I hate doing anything like that, I hate questioning someone doing their job, but it's my body.* (Sarah).

Participants discussed different reasons why they assumed characteristics of the consumer persona during their MET encounter. It is interesting to note, rarely did a participant adopt these characteristics during their entire experience. Instead there seemed to be an oscillation between the recipient and consumer persona. In summary, Rose described the movement between the two personas:

> *You come through the front door of the hospital and you just go into the zone. You put yourself in their hands and to a large extent you must always keep in the back of your mind that it is you. You must look after yourself and push your own barrow to a certain extent, but you know they're experts, you've got to put yourself in their hands, and you pick up all your stuff when you go out the door.*

5.5.4 Being in Good Hands

From the perspective of the participants in this study, many perceived they were 'in good hands' with their MET. The term 'in good hands' has previously been described as being in protective care, in competent or safe care, being handled or cared for by a competent party, and being in a position to be well cared for (Chiarelli, 2011; Hébert, 2017; Macquarie Dictionary, 2019; Whyte & Waters, 2009). Participants interviewed used various terms to qualify their perceptions of being 'in good hands': '*trust*', '*confidence*', '*well trained*', and '*safe*.' Being 'in good hands' was commonly described by participants as having trust and confidence in the MET's abilities to care for them and save their lives.

In this study, the concept of 'trust' was defined as having faith in a person's ability and characterised by a belief or an attitude bound in time and place, a confident reliance on someone and a willingness to engage in a relationship while accepting one's consequent vulnerability (Dinc & Gastmans, 2012). Trust and confidence, associated with the MET's competence and expertise in a demanding situation, was regularly reported by participants. In trusting the MET, participants had confidence in the decisions they made to save their lives. Paula trusted the MET to respond to her medical needs, to be thorough and make sensible decisions regarding her care. She explained: "*I trusted that I would be well looked after by the team…when I told them I was having trouble, they just leapt straight into action."*

Before Paula's MET encounter, she discussed being cared for by nurses who she described as competent. She described competent nurses as "well trained" which gave her confidence in their ability to care for her, especially when she became acutely unwell. This established trust influenced Paula's perception of the MET. This was similar for Rose who associated the trust and confidence she had for the MET to their "attitudes and their expertise". She explained that they took over her care when she did not feel up to much which also made her feel safe, Rose said, *"I wasn't up to doing anything much and they just took over, and I felt quite safe in their hands."* Joan explained it was the structure and approach of the MET that gave her confidence, she described it as a "beautifully structured team" that: "*gives you a lot of confidence even if you think you are on your last breath, you think, thank God you are in really good hands*."

Trust and confidence were found to have developed when participants considered members of the MET approached them with a demeanour that was sensitive to their needs. For example, Anna did not want to be resuscitated if she went into cardiac arrest during her MET encounter, wishes that were respected by her MET. Anna said: *"they did ask me because I am a do not resuscitate, if I still considered that…I said 'yes'…I knew they would let me go if I had enough."* Trust and confidence also developed when the MET ensured participants were informed. Trust was also nurtured when participants were encouraged by the MET to be involved in making decision about their own care. For example, Paula explained: "*They kept me well informed of what was going on with everything…every question I asked was answered. They explained to me anything I wasn't sure of…they were very approachable, very reassuring. I was in good hands."*

Also, trust was established when participants perceived that the MET had formed a treatment plan based on accurate assessment of the individual's physical condition. When participants felt that the MET had thoroughly assessed them, they were more inclined to trust their management plan. Daniel explained: "*They had my books out. Going over the books all the time. Checking out what I'd had and what I hadn't had to see what caused it. They were asking me questions…I just thought I'm in good hands."* Participants felt a sense of security knowing that if they deteriorated, they would be effectively cared for: "*I know if I had another turn, they'd be on the job in about two seconds flat, I know it"* (Mary). Mary felt that by simply communicating her concerns to the MET meant that she would be managed effectively and that she would comply with recommendations. She qualified this by explaining:

> *I reckon they have done what they think is right, I found them extremely good. The nurses you couldn't get better if you tried…They checked over me, they x-rayed me, they put the heart thing on me. They listened to my chest and back, stuff like that…"*

However, when participants felt that they had not been thoroughly assessed by the MET, that their acute deterioration could have been avoided or they had a prior negative experience they were less likely to trust the MET's treatment and management plan. Sarah said:

> *This was my second one. I had one while I was in intensive care. Similar, it was the same medication, so I don't know why I was given it again. I didn't think to ask about that. I just trusted that my care would be taken care of…*

Tara's previous experience of acute deterioration and a MET encounter was due to a medication error by healthcare professionals. This previous experience influenced the trust she had for the current MET. The development of trust in a relationship occurs as a dynamic process (Lee, 2006). Both Tara and Sarah explained how the development of trust in healthcare professionals was ongoing. Tara qualified this by explaining:

> *I think the fact that I'd been overdosed in the past… I thought if they've got that wrong, what else could they get wrong? Once you've had a fright like that it doesn't leave you…I'd keep apologising, saying 'Look it's not you. It's just that I've had this bad experience, I've got to find out what you're giving me. Why you are giving me that drug?*

5.5.5 Facing Death

During their MET encounter, some participants were unsure if they would survive. They focused their attention on what they perceived as vital survival tools; members of the MET and equipment: *"In normal circumstances, you would feel physically invaded. But I was feeling so ill, I left myself completely open to the mechanics and said, "well whatever is going to be is going to be."* (Henry). Therefore, members of the MET became valued, respected and appreciated to help them survive. Interestingly, participants accepted however they were treated by the MET because they were seen as an essential part of their survival. For example, when Terry presented to the emergency department with shortness of breath where he was unsure if he would survive; *"I thought I was going to die. I thought this is the end."* During this uncertainty, Terry trusted the MET and the equipment they were using to save his life. He demonstrated this by following their instructions, being compliant, passive and accepting dependency. Characteristics and behaviours that are different to his normal behaviour. Terry admitted that when not in a life-threatening situation and being uncertain about his survival he was fiercely independent, stubborn and usually delays seeking help: *"I was such an idiot, I was stubborn and I let it get to this point*."

Yvonne spoke about being annoyed with the nurse who was caring for her when her MET encounter was initiated. She described him as 'grumpy' and would normally not tolerate being spoken to in that way. But, he was part of the MET that saved her life and she was grateful to be alive, explaining:

> *I am not 100% sure what happening…I didn't ask questions because I had a grumpy male nurse…but I wasn't about to complain. Normally I would have wanted to make a complaint, but I didn't. Under the circumstances, my health was at risk, so I just moved on.*

When not questioning his survival, Henry admitted to being an independent and highly intelligent person who questioned everything and would complain if necessary. While being uncertain of his survival, he also adopted a manner incongruent to his normal self. He was passive, non-demanding and accepting of his dependency on the MET. Henry explained: *"You see I'm normally or I would like to think I am, a reasonably intelligent person that asks questions, but that would give question on this occasion...I had given myself over."*

When survival was uncertain, some participants focussed more on their bodies and less so on people and the environment. For example, Sam experienced acute deterioration and a MET encounter after waking up in hospital and feeling unwell. Throughout her MET encounter Sam thought she was going to die and paid little attention to people and what was happening around her. Sam's focus was on staying alive and seeing her animals again, Sam said: *"I won't ever see my animals again…it's just something, I knew the way I felt, I was finished."* Jill also recounted limited situational awareness during her MET encounter. The life-threatening nature of her condition caused her to focus on herself: *"I really can't remember the treatment or what they had done…I had low blood pressure and a high heart rate, I was a pretty crook."* Alex had thoughts of death during her MET encounter and even though her focus was mostly on her physical symptoms, she was aware of her environment and grateful to have members of the MET by her side:

> *It was such a relief to know that somebody was there to help. Sorry, I'm getting all emotional…I thought I was going to die but I wasn't going to die alone because I had plenty of people (MET) around me.*

When facing death, some participants recalled experiencing hallucinations and dreams during and after their MET encounter. During her MET encounter, Amber described being pulled through a tunnel which she associated with a near death experience: "*It was at one stage during one of the MET calls, I could see myself being pulled back through a tunnel. They did tell me I nearly died so maybe that was it."* Amber described the experience as scary and the visions continued for a period after her MET review: *"Then after it all happened, every time I closed my eyes for a few hours that seemed to happen."* George also experienced hallucinations during his acute deterioration and MET encounter which he attributed to a near death experience. He described feeling "*strange*", like being in a "*black tunnel…it was quiet and felt like nothing*", before "*drifting away*", he was positive "*this was death*." George recalled waking and being relieved at being alive: "*I just felt good and happy to be alive…in my mind I died, it was a weird experience.*"

Facing death in whatever form, personal, actual, imagined or feared, was a major aspect of participants' experiences of acute deterioration and MET encounter. It is so powerful in its impact that some participants such as George and Sarah questioned their mortality, the meaning of life and what it meant to be alive. George said: *"I've never feared dying but you realise your own mortality is there…I am a very determined person and I am not going to die, I have a strong commitment to live which I believe is like positive thinking."* Sarah also explained: *"It's just made me realise my mortality a bit more. I'm facing that more and more and I think having the MET call makes me face it (death)."*

5.6 Category Three: Reflecting on the Event – After the Encounter

In this study, the term 'reflection' is concerned with consciously looking at participants' experiences, actions, feelings, and responses of their acute deterioration and MET encounter (Atkins & Murphy, 1994). The participants' need for knowledge and understanding about their illnesses was of great importance for their self-care and recovery. Some participants searched for deeper understandings about their illness and the events that occurred, whereas others were less reflective and felt they could manage without further understanding. The category, *Reflecting on the Events – after the encounter,* explores the participants' processes of reflection and is further conceptualised through five sub-categories: *Experiencing an impact; Seeking an understanding; Accepting of events; Wanting to be seen;* and *Advising others.*

5.6.1 Experiencing an Impact

When describing their experiences of acute deterioration and MET encounter, some participants explained feeling like they had lost confidence, especially in their physical condition. Since her episode of acute deterioration and MET review, Vera explained feeling like she had lost confidence and tended to panic since when she experienced symptoms related to her chronic condition:

> *I reckon, now that I think about it. Up until then (MET encounter) I was cruisy, accepting every day as it came. After that I lost my confidence and I panic more now when I have trouble breathing…It has made me more aware and I ask the nurses all the time to check my stats, when they do and they are ok I feel reassured.*

Vera explained the impact this loss of confidence had on her ability to cope with symptoms associated with her chronic condition. She explained requiring support from a psychologist to manage her anxiety:

> *It's opened my eyes to how serious things are, how serious my breathing is, to the extent that I have started to see a psychologist here. I didn't have a bad experience, but it has opened my eyes up to how quickly my stats can go down, how breathing is so important and now I'm scared that I might have trouble breathing.*

When asked what could have helped to address the impact of loss of confidence, Vera suggested that all patients who experience acute deterioration and a MET encounter should receive: *"a debriefing, they provide nurses with a debrief."*

Participants also experienced feelings of uncertainty: "*I wonder if this feeling's going to be here forever…I've experienced nothing like it before."* (Sam). Uncertainty was generally expressed towards unanswered questions participants had about what happened. According to Beth, *"you tend to question yourself, like what happened? But no one is there to answer, it's just part of it. So, I don't know whether the staff can answer that, I don't know."* Daniel also had unanswered questions about what occurred during his acute deterioration and MET encounter: "*I still don't know what happened and I have questions that haven't been answered".* When asked what impact this has had on him, Daniel said, *"I suppose it makes you think a bit…You think there's something really wrong."*

There was considerable discussion about participants becoming more aware of their physical health as a result of experiencing acute deterioration and a MET encounter. Julie, for example, did not realise how unwell she was: *"It made me realise I am sick…and how precious life it."* Being aware was also expressed towards their conditions and tended to relate to taking control of their bodies. Trudy experienced a time of denial towards her chronic condition which affected her daily life. Rather than go to the hospital as directed by her GP when her symptoms became worse, she went home and tried to ignore it until she had no choice but to call an ambulance because she kept *"passing out"*. She said: *"He (GP) told me to come straight down to emergency, instead I went home…next thing I know an ambulance is coming and I am at triage."* The experience had an impact on Trudy who said:

> *You must realise you have to change so if you don't change its going to be the same all the time. Because it's gotten into a stage, I can't even cross the road and I didn't want to go out and I had to get friends to go shopping for me.*

Sarah used the term 'aware' to explain the impact experiencing acute deterioration and a MET encounter had on her: "*it has made me aware that my self-care is really important and self-checking all the time, not just relying on things being okay.*" She qualified this by explaining:

> *You need to be responsible for your own care as well, which I certainly haven't been doing. I've come to hospital and I'm very sick when I'm here and I just allow people to put needles in my feet because they couldn't find a vein elsewhere. I've allowed all sorts of things. I've allowed one young nurse do terrible things to me. Now I look at it and think, no I don't have to put up with it. I didn't in the finish.*

As discussed previously, participants also become more aware of their mortality as a result of their acute deterioration and MET encounter. Sarah and George explained how their experiences made them face the reality of death and that preparations need to be made. Sarah said:

> *I have to be thinking more about what I need to do and preparations that I really do need to have…I'd been facing up to things for a while, but that MET call was something that puts things (morality and death) more in front of me.*

One participant believed she had become more empathetic and informed as an outcome from experiencing acute deterioration and a MET encounter. June explained it was the way she had been treated by the MET that had an impact of her ability to empathise with others. When asked if the MET encounter had an impact on her, June said:

> *I reckon it might have…just being more empathetic towards people and how they react to situations because you don't know until you are put in that situation and you can sort of sit back and reflect…Just say if I was in a situation where somebody's struggling and I now could go up to them and go, 'I just want to help you.'*

5.6.2 Seeking an Understanding

Following their acute deterioration and MET encounter, participants reflected on their experiences and considered what advice they would give to other patients. From the perspectives of participants in this study, there was some commonality in their interpretations of how patients should approach their own acute deterioration and MET encounter.

5.6.2.1 Questioning What Happened

Following their acute deterioration and MET encounter many participants questioned what had occurred. Participants repeatedly commented that they did not know what happened, what was done and why or they were told some information after their MET encounter by their bedside nurse: "*the nurse told me bits and pieces, but the others (MET) just sort of went.*" (Tara). Like Tara, other participants had to contend with frequent unanswered questions: "*they tend to disperse…they don't answer any questions, they are ready to move on*" (Beth). As previously discussed, Tara had a negative experience and felt her acute deterioration and MET review could have been avoided. Although she was aware that a medication error was the cause of her experience, unanswered questions remained. When asked if she had any advice for patients who may experience acute deterioration and a MET encounter, Tara said: "*question everything.*" This approach was supported by Vera and June, with June encouraging patients to not hold back when trying to understand what is happening to them: *"Don't hold back, ask questions...understanding what is happening to your body is so important, don't leave any question you may have unanswered."* Vera also said: *"ask questions, because I wasn't 100% sure what happened and it's overwhelming."* Since her experience, Tara approached her care very differently. She admitted to having a recipient persona during her previous admissions and MET encounter but since had adopted characteristics of the consumer persona. Although she was apologetic in her approach, she subsequently questioned everything, especially medication she was given, whereas before she did not. She did not have total confidence in the healthcare professionals caring for her. Tara explained:

> *I keep apologising, saying to the nurses, "Look it's not you. It's just that I've had that bad experience in there." I said, "I've got to find out what you're giving me. Why are you giving me that drug?" Like they're giving me Endone and I'd say, "How much Endone are you giving me?*

In summary, seeking understandings of the events that occurred was commonly discussed by participants. Many discussed their understanding towards the MET and the nature of the event but were left with uncertainty. This was the main theme discussed by Beth who understood the MET's need to move on but wanted her questions answered to be reassured that she was alright. She explained:

> *I think that after the MET call they tend to disperse and you want to know what happened, but they don't answer any questions, they are ready to move on. I understand that because they've got other things to do. So, I would say, not that reassurance, but that just something*

> *to give you a bit more confidence that everything is alright. I'm not saying they don't do their job, but it's like 'okay we have sorted this one, let's move on.*

5.6.3 Accepting of Events

As explained by participants, this sub-category describes the journey to acceptance. Acceptance was not discussed by all participants because those who had experienced acute deterioration and a MET encounter previously had already gone through the process of acceptance. Instead, they discussed other aspects of their experience that was significant to them. Nonetheless, it was evident that an individual's experience involved dealing with a potentially life-threatening illness, being a patient, and depending on what stage of acceptance participants were dealing with, their experience of acute deterioration and MET encounter differed. Fear and uncertainty was commonly discussed by participants as being part of the journey to acceptance: *"It's frightening but it's just one of those things…when you're in situations like that you don't know what is going to happen but you've just got to accept it, can't do nothing about it."* (James). The process of acceptance also involved accepting what the MET needed to do, even if that participant thought it was unnecessary. For example, during Beth's MET encounter her symptoms subsided and her condition improved to a point where she: *"felt fine, so to me it was a false alarm."* She heard a member of the MET request an electrocardiogram (ECG) and thought: *"You don't really have to, but it's a process thing that's set in place and you (the patient) have to go with it, you might not want it but you have to go through it."* For some, the process of acceptance began before experiencing their MET encounter: *"I have been deteriorating lately. I accept that and I accept what happened (the MET encounter). It's not often that I accept things like that."* (Henry).

Finding purpose is another element of illness acceptance. For George, despite his ailing chronic condition and previous near-death experience, illness acceptance came in the form of commitment to survive and to life live to the fullest despite his condition. George explained:

> *I am determined to get better. I spent over two weeks or whatever in the hospital with a bacterial infection. I was sent home thinking I was alright, but I never felt 100%, the next thing I was back in hospital with the same thing and I went through probably more because I had lost weight and my conditioning was right down. I was very vulnerable so I knew I wasn't in a good place when I had the MET call, but I just accepted, yep I will get better.*

When on a journey to acceptance, participants had to work through a range of emotions. For some, the emotions they experienced such as uncertainty, fear and anxiety made it challenging for them to move past what had occurred. Even though participants commonly experienced these emotions throughout their acute deterioration and MET encounter, they were intensified after the event and on reflection. Vera, for example, explained that as a result of her MET encounter her anxiety had intensified: *"…Up until then (MET encounter) I was cruisy, accepting every day as it came. After that I lost my confidence and I panic more…"* Once participants worked through these emotions they were able to experience some form of acceptance: *"I'm handling it pretty well. With everything that's been going on…I have accepted a lot of things along the way and I know what's going to happen and all of that when a MET is called."* (James).

5.6.4 Wanting To Be Seen

Many participants noted that the focus during their acute deterioration and MET encounter was on their physical symptoms. Participants acknowledged that important aspects of their emotional wellbeing were not considered, instead their deteriorating condition became their defining feature: *"like someone did say to me, oh…you are going to be alright but that was all."* (Amber). Participants discussed the importance of 'being seen as a person' and the MET's failure to 'see the person in the patient' was deeply felt by individuals: "*they (MET) mustn't lose sight of the fact that the patient is actually a real person that doesn't have their knowledge and their expertise."* (Rose). During her MET encounter, Angela felt the team did not pay attention to her, leaving her feeling excluded: "*…as more and more people came in, I wasn't really involved*." Angela further explained:

> *…there was only one point, which is they were so busy talking about me they didn't pay attention to me, like when I was throwing up, like I would have loved some water to rinse my mouth out but I wasn't allowed, so I just wanted a tissue to wipe my mouth out after I finished.*

In summary, Angela described her experience of a MET encounter as "*you're definitely a number*" and she advised METs to "*see the person in the patient, pay attention to the patient as well as all the other stuff*." Sarah had a similar experience to Angela, although Sarah recognised what the MET was doing was "*for her own good*", she was not included in the process:

> *Even though that doctor had seen me before and she had the team around her, they were very busy. They were very busy asking questions. You know it's all for your own good because it's all about you but they're looking at and suggesting different tests and whatever, you know that it's all for your won good but you're not really part of that.*

This had a significant meaning for Sarah because when asked what advice she would give to the MET to improve their experience she said:

> *…to recognise that even though the patient can't articulate that they are still in there and listening and getting some of what you're saying. And if you could include them a little more, even if you don't really think that they're with it, possibly they are. Perhaps include them a little bit more in what you're doing, and tests you're thinking of doing and why you're going to do them. You can knock and think there's nobody's home but there is someone home in there.*

Along with being seen as a person, participants wanted the MET "*to have a more caring nature*" (Tara), "*be a bit tactile or touch the person, speak to them, just a hand on the shoulder*." (Amber), to have a "*good bed side manner*" (Tim), and "*to communicate well, have compassion and treat them as an individual*" (Anna). To Anna being seen as a person meant being shown compassion and understanding. She further explained:

> *Treat them (patients) as individuals that have their own working brains…Give them the opportunity to speak and listen to what they want to say. And if they (patients) say, "Just let me go. I don't want to resuscitate." Try and understand their point of view instead of trying to say, "Yes, but…" If that patient's decided I've had enough, let me go.*

Like Anna, many participants commented that better communication from the MET would have helped them be seen as a person: "*probably every detail that they were talking about being explained to me or being close to me. They were further apart from me when they did things…being part of the decision-making, not being just the patient. Being a person is really important*" (Sarah). In fact, those who perceived the communication to be positive during their MET encounter, felt included in the decision-making process. Communication and being part of the decision-making process was important to participants because it meant that someone was looking at them as a whole person with feelings and concerns, rather than objectified as a physical body.

5.6.5 Advising Others

When reflecting on their experiences and considering what advice they would give to others who may be in the same position, participants discussed the importance of "*looking after your health*" (Terry), to not "*hang about*" (Mary), "*not to hesitate*" (Sarah), "*hang in there*" (Tara) and to "*think positive*" (Brian and George). Mary felt she stayed at home for too long when she started to experience symptoms instead of calling for help, *"Don't hang about at home for too long. I mucked around a bit about whether I should have come in or not and I should have. Definitely come in quicker."* Similarly, Sarah's advice was to not hesitate in calling for help as soon as you feel unwell:

> *Do not hesitate. I was having an infusion like an antibiotic running through my PICC line at the time, which possibly what I was having a reaction to…For whatever reason if you're feeling a bit strange, ring your bell, tell your nurse. If it's nothing, its nothing. It doesn't matter. It's no skin off anyone's nose. Don't be afraid to ring your nurse and say, "Look, I'm feeling a bit strange." I went from telling her that to going down very quickly. And I doubt that I could have rang the buzzer five minutes later.*

On reflection and despite experiencing the difficulties associated with acute deterioration and MET encounter, participants also generally remained optimistic and encouraged others who may experience the same to: "*hang in there because you'll get through it in the end, which is what you do. But it's a pretty sad and sorry road."* (Tara). Brian remained positive during his experience and he recommended that others do the same: "*try to keep yourself positive as much as possible. Remember that your body may be sick, but your brain is not. So, if you think that you are not sick, then you are not sick."* George had a similar outlook during his experience and was "*determined to live*". Throughout his many hospital admissions and his previous MET encounter he had never feared dying. He believed this was because he was "*a very determined person*" and had a "*strong commitment to live*." Therefore, George recommended others who may be in a similar situation as he was to "*think positive, it helps*."

Participants talked about the importance of 'going with the flow' when experiencing acute deterioration and a MET encounter. Participants were unable to control aspects of their experience and therefore many suggested that patients who are faced with the same situation as theirs need to adopt a passive approach: "*they (MET) are here to help you and make you comfortable, so just go with the flow.*" (Vera). According to Amber, *"you just have to go with the flow, just let it happen, fight, of course, you have for to really fight."* Beth used the term 'going with the flow' to explain how patients need to be guided by the MET. As well as going with the flow and being guided by the MET, she explained that the MET are professionals whereas patients are novices:

> *There are a lot of people around and you have to go with the flow, be guided by them. They are the professionals and to a novice, it's not overbearing, not intimidating. I don't know the right word, but you think you have just got to be guided by them.*

Many participants discussed the importance of listening to the MET to help with their fear and feelings of being overwhelmed: "*look it is overwhelming but listen to what they are saying…if you listen to them and not go into fear, they will help you through the stress."* (Margaret). Alex described the MET as "*knowing what they are doing*" as the reason to listen to them, he qualified this by explaining: *"We (patients) think we know but we don't, because I'd been putting it off for days to* *come to a doctor and I shouldn't have. If I had of gone, I probably wouldn't have been here now."* Acceptance was also discussed by participants in the context of taking the advice provided by the MET: *"just take the advice, let them do their job, take their advice."* (Trudy). Acceptance was also generally discussed by participants who had experienced a MET encounter before. James explained:

> *The first time (MET encounter) is a bit scary, you don't know exactly what's going to happen. Patients have got to learn to accept what they do (the MET) and what is going to happen. You need to accept that they're there to help and they will look after you.*

For James, not interfering with the MET also came with acceptance: *"You need to accept they've got a job to do. You can't interfere. You can't tell them what to do or how to do it or when to do it, they all know what they've got to do."* James also explained acceptance as having "faith" in the MET and to be "prepared to cooperate" and by doing this you are "working together":

> *Just to have faith in the nurses and be prepared to cooperate with anything they want to do with you and not to work against it, accept it and just be helpful…because they are looking after your health and I think the more help they can get from you as a patient the more help they can give to you in return…I just believe in working together to rectify the situation you are in.*

5.7 Summary of Chapter Five

This chapter provided a comprehensive discussion of the study results along with participants' demographic information. From the study data, three constructed categories were generated: *Experiencing changes – before the encounter; Perceiving the reality – the encounter;* and *Reflecting on the events – after the encounter* and a detailed account of each, including the subcategories, was provided. The generated categories have a clear interdependent relationship with factors emerging from one category that had an impact on another. The following chapter presents the overarching theory, which offers an abstract rendering of the participants' actions and meanings when engaged with the core process.

CHAPTER SIX

The Theory

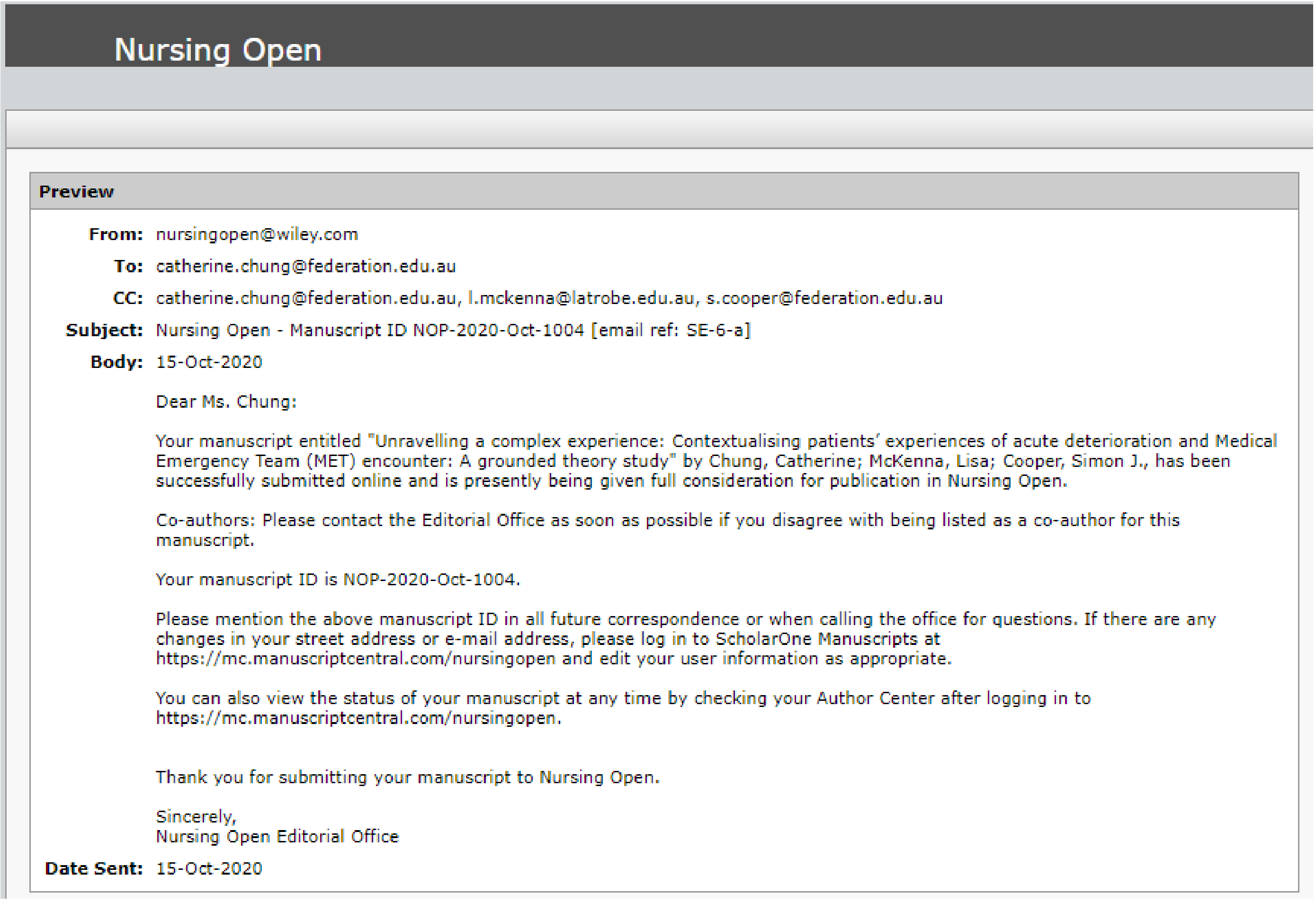
Chapter Six: The Theory

6.1 Introduction

This chapter presents the theory constructed from the study data. The theory was developed with a rigorous process of concurrent data collection and analysis, which centred on the core process. This basic social process is evident in three main categories embodied in the theory. Contextual determinants that mediate the core process are discussed in Chapter Seven. The findings from this chapter are presented in the form of a manuscript submitted to ‘Nursing Open’ for publication and is currently accepted subject to minor changes.

Paper 2

Chung, C., McKenna, L., Cooper, S.J. (submitted). Unravelling a complex experience: Contextualising patients’ experiences of acute deterioration and Medical Emergency Team (MET) encounter: A grounded theory study. *Nursing Open* (Submitted in Oct 2020)



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Your manuscript entitled "Unravelling a complex experience: Contextualising patients' experiences of acute deterioration and Medical Emergency Team (MET) encounter: A grounded theory study" by Chung, Catherine; McKenna, Lisa; Cooper, Simon J., has been successfully submitted online and is presently being given full consideration for publication in Nursing Open.

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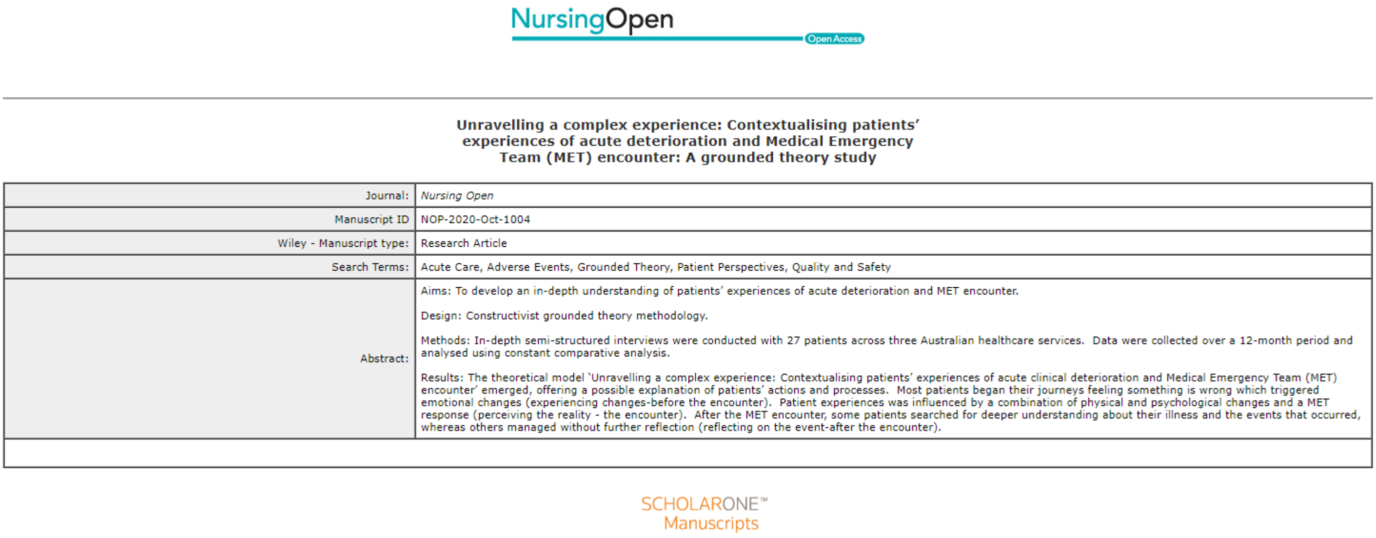

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Unravelling a complex experience: Contextualising patients' experiences of acute deterioration and Medical Emergency Team (MET) encounter: A grounded theory study

Journal:	*Nursing Open*
Manuscript ID	NOP-2020-Oct-1004
Wiley - Manuscript type:	Research Article
Search Terms:	Acute Care, Adverse Events, Grounded Theory, Patient Perspectives, Quality and Safety
Abstract:	Aims: To develop an in-depth understanding of patients' experiences of acute deterioration and MET encounter. Design: Constructivist grounded theory methodology. Methods: In-depth semi-structured interviews were conducted with 27 patients across three Australian healthcare services. Data were collected over a 12-month period and analysed using constant comparative analysis. Results: The theoretical model 'Unravelling a complex experience: Contextualising patients' experiences of acute clinical deterioration and Medical Emergency Team (MET) encounter' emerged, offering a possible explanation of patients' actions and processes. Most patients began their journeys feeling something is wrong which triggered emotional changes (experiencing changes-before the encounter). Patient experiences was influenced by a combination of physical and psychological changes and a MET response (perceiving the reality - the encounter). After the MET encounter, some patients searched for deeper understanding about their illness and the events that occurred, whereas others managed without further reflection (reflecting on the event-after the encounter).

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Abstract

Aims: To develop an in-depth understanding of patients' experiences of acute deterioration and MET encounter.

Design: Constructivist grounded theory methodology.

Methods: In-depth semi-structured interviews were conducted with 27 patients across three Australian healthcare services. Data were collected over a 12-month period and analysed using constant comparative analysis.

Results: The theoretical model '*Unravelling a complex experience: Contextualising patients' experiences of acute clinical deterioration and Medical Emergency Team (MET) encounter*' emerged, offering a possible explanation of patients' actions and processes. Most patients began their journeys feeling something is wrong which triggered emotional changes (*experiencing changes-before the encounter*). Patient experiences was influenced by a combination of physical and psychological changes and a MET response (*perceiving the reality - the encounter*). After the MET encounter, some patients searched for deeper understanding about their illness and the events that occurred, whereas others managed without further reflection (*reflecting on the event-after the encounter*).

1. Introduction

Acute patient deterioration describes the "physiological, psychological or cognitive changes that may indicate worsening of a patient's health status occurring over a period of time" (Australian Commission of Safety and Quality in Health Care [ACSQHC], 2017, p.63). Over the last 20 years considerable effort has been made, around the world, to ensure hospital patients who deteriorate receive appropriate and timely care ([redacted]). Research suggests that hospitals have increasing numbers of patients who are more likely to become seriously ill during their admissions due to complex problems ([redacted]). Recently, patient experience has been recognised as a means of assessing healthcare delivery with healthcare services across the world gathering patient experience or satisfaction data (Edwards, Duff, & Walker, 2014). However, little is known about patients' perspectives of experiencing acute deterioration ([redacted]). Our study addresses this gap by exploring patients' experiences of acute deterioration and being cared for by a medical emergency team (MET).

Background

Globally, policy makers are placing greater emphasis on patient safety by gathering patient experience and satisfaction data (King, Peacock, Crotty, & Clarke, 2018; World Health Organisation [WHO], 2006). The literature suggests that positive patient experience is linked to high quality healthcare, improved patient safety and reduced length of hospital stay (Edwards, Duff, & Walker, 2014; Wolf, Ekman, & Dellenborg, 2012; ACSQHC, 2017). Although the significance of patient experience or satisfaction data is unquestionable, absence of the patient's voice in the acute deterioration literature is pertinent ([redacted]; Guinane, Hutchinson, & Bucknall, 2018; Drenth, 2013). To date, there has only been a small number of studies examining patients' experiences of acute deterioration ([redacted]).

Patient safety as defined by WHO (2017) is "the absence of preventable harm to a patient during the process of health care and reduction of risk of unnecessary harm associated with health care to an acceptable minimum." [redacted] and Guinane et al., (2018) suggest that healthcare services are caring for an increased number of patients with complex chronic medical conditions who are at risk of acute deterioration and adverse events. In a report prepared by WHO (2017), globally there are approximately 421 million hospitalisations per year with 42.7 million adverse events occurring during these admissions (WHO, 2017).

Across the world, countries have developed standards to prioritise quality improvements in health and social care. For example, in Australia, the National Safety and Quality Health Service

(NSQHS) developed eight standards to ensure that expected standard of safety and quality are met (ACQSHC, 2017). Included in these standards are: *Standard 2 - Partnering with Consumer Standard* focussing upon the need for high quality healthcare and improved patient safety to enhance patient experiences (ACQSHC, 2017). In the United Kingdom, the quality standard, *Patient experience in adult National Health Services (NHS),* was developed by the National Institute for Health and Care Excellence (NICE) to ensure patients are treated with respect, honesty, understanding, dignity, compassion and respect ([redacted]; NICE, 2018).

Track and trigger system to predict acute deterioration have been implemented globally (Cant & Cooper, 2017). The importance of early detection and management of acute deterioration has been reflected in the emergence of rapid response and medical emergency teams (MET) (King et al., 2018; Cant & Cooper, 2017). These teams provide fast and intensive medical treatment for patients experiencing acute deterioration when activated by a healthcare professional, more often the patient's bedside nurse. Although, research suggests that patient deterioration, predicted by close observations of vital signs, is not always appropriately acted upon ([redacted]; Stickland, Pirret, & Takerei, 2019; Currey, Allen, & Hones, 2018). Stickland et al., (2019) conducted a qualitative cross-sectional study on patients' perceptions of deterioration and the need for a patient and/or family-activated rapid response service to reduce adverse events. According to the authors, a Patient and Family Activated Escalation System (PFAES) has been established to enable patients and families to escalate their concerns. The findings suggest overwhelming support by patients and family members but acknowledge that further research is required (Strickland et al., 2019).

2.1 Objective

The purpose of this study was to generate theory about the process's patients engaged in when experiencing acute deterioration and MET encounter.

1. Design and methods

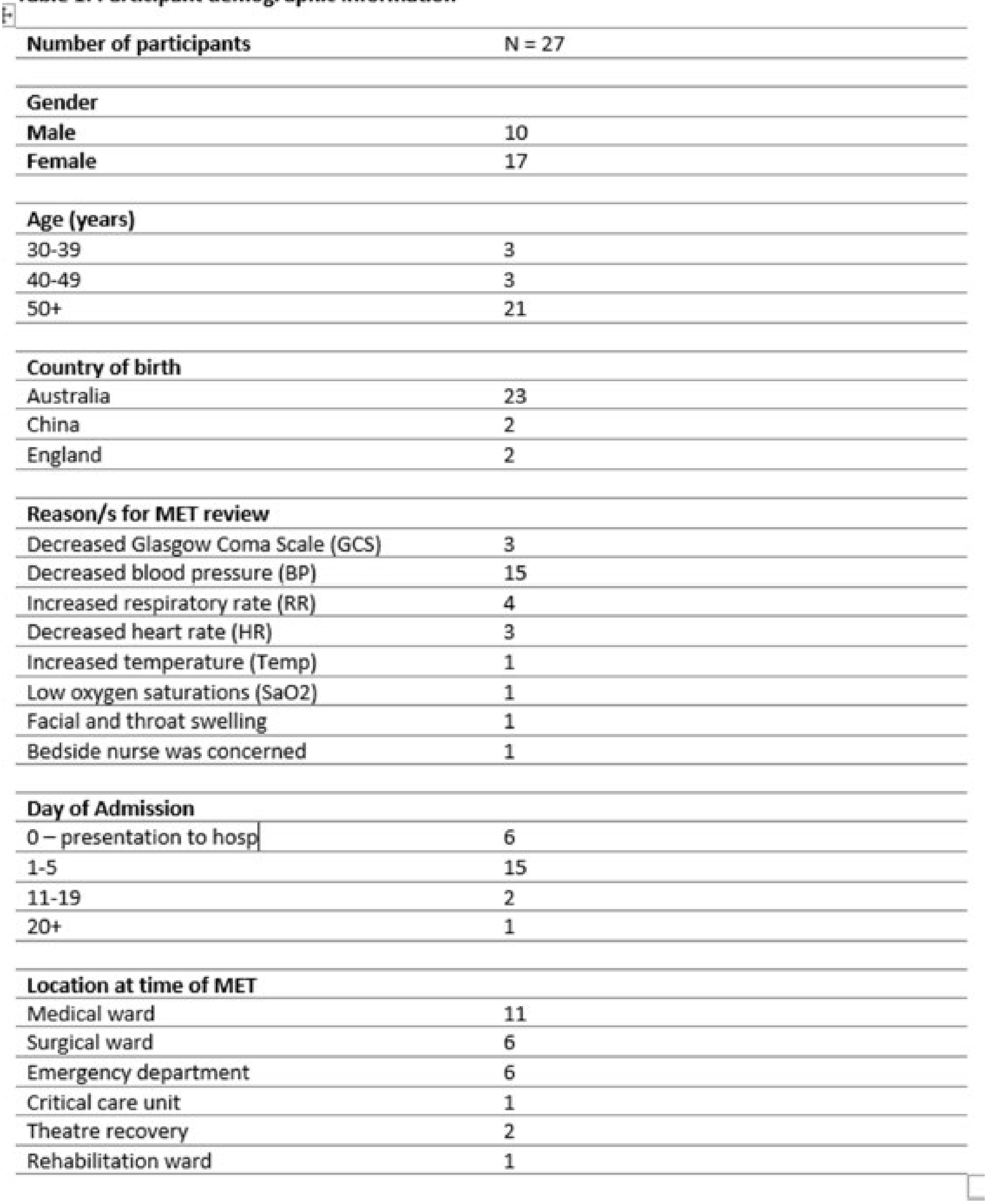
The consolidated criteria for reporting qualitative research (COREQ) checklist was applied to enhance quality and transparency of this study. The study used a constructivist grounded theory (CGT) approach (Charmaz, 2006; 2014) to develop a theoretical understanding of patients' experiences of acute deterioration and MET encounter. Grounded theory (GT) is an inductive approach to theory construction that identifies actions, interactions, behaviours and processes (Corbin and Strauss, 2008). According to Charmaz (2006), GT is "a method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data" (p. 187). GT is appropriate when there is little theoretical understanding about a phenomenon and the generation of theory with explanatory power is a desired outcome (Birks & Mills, 2015).

CGT was considered suitable for this study from its ontological, epistemological and methodological underpinnings. During the research process, CGT requires a position of mutuality between participant and researcher and data analysis is interpretative rather than predictive (Charmaz, 2014). Individuals construct reality "under the influence of a variety of social and cultural factors that lead to shared construction" (Howell, 2013, p. 90). In this study, the constructed theory is a shared reality and understanding between the researcher and participants about what it is like to experience acute deterioration and MET encounter.

3.2 Participants

Using purposive and theoretical sampling, 27 patients were recruited from three Australian healthcare services, between May 2018 – May 2019. Patients over 18 years of age who experienced acute deterioration resulting in a MET review were invited to participate. Patients were excluded if they were confused and/or unable to provide informed consent, assessed as clinically unstable by a hospital clinician, an obstetric patient, had an active complaint against the hospital, a mental health unit inpatient or under a mental health team. Demographic characteristics of participants are presented in Table 1.

Table 1: Participant demographic information



Number of participants	N = 27
Gender	
Male	10
Female	17
Age (years)	
30-39	3
40-49	3
50+	21
Country of birth	
Australia	23
China	2
England	2
Reason/s for MET review	
Decreased Glasgow Coma Scale (GCS)	3
Decreased blood pressure (BP)	15
Increased respiratory rate (RR)	4
Decreased heart rate (HR)	3
Increased temperature (Temp)	1
Low oxygen saturations (SaO2)	1
Facial and throat swelling	1
Bedside nurse was concerned	1
Day of Admission	
0 – presentation to hosp	6
1-5	15
11-19	2
20+	1
Location at time of MET	
Medical ward	11
Surgical ward	6
Emergency department	6
Critical care unit	1
Theatre recovery	2
Rehabilitation ward	1

3.2 Data Collection

Once patients met the inclusion criteria they were provided with an explanatory statement and consent form. Patients who chose to participate returned consent forms agreeing to partake in a recorded interview. Once a patient consented to be interviewed, a mutually agreeable time and place was agreed upon. Altogether, 27 interviews were conducted, 24 occurred at the participant's bedside and three were conducted in the ward's visitor room to ensure privacy as these participants were in shared rooms. One-on-one interviews occurred, using a semi-structured format with some guiding questions (Table 2). To elicit participant responses, an initial interview guide was used. The interview guide was evolving with additional questions added after analysis of previous interviews. Interviews were approximately 10-30 minutes in duration, audio-recorded and later transcribed verbatim. Each interview began by outlining the study purpose, ensuring the protection of their identity and how information gathered would be stored.

TABLE 2: Example of initial interview questions

Tell me about how you came to be in hospital?
What is your understanding of the reason you were admitted to hospital and your management plan?
While in hospital and before your medical emergency team (MET) review, when, if at all, did you first experience or notice that your condition had changed? If so, what was it like?
If you recall, what were you thinking then? Did anyone or anything influence your actions?
What happened next?
Could you describe the events that led up to your MET review?
Can you tell me about your experience of being cared for by a MET? What were your thoughts and feelings during this time? Did anyone or anything influence your actions?
Could I ask you to describe the most important part of your experience?
What happened next?
How would you describe your condition before, during and after your Met review?
As you look back on your experience, do you have any advice for the MET?
Looking back, do you have any advice for a patient being who experiences acute clinical deterioration and MET review?
Is there something else you think I should know to understand your experience better?

3.3 Data Analysis

Initial, focused and theoretical coding was used to analyse the data (Charmaz, 2006; 2014). Table 3 offers an example of how raw data were categorised. In keeping with the principles of grounded theory, concurrent data collection and analysis occurred until all concepts were fully explored (Hall, Griffiths, & McKenna, 2013). Initial and focused codes were generated from interview transcripts and then raised to sub-categories. Sub-categories were further developed using constant comparative methods to a level where emerging categories were compared to codes and emerging concepts (Hall et al., 2013). A reflective diary was maintained throughout and theoretical memos were created as a means of conceptualising the data (Charmaz, 2014; Hall et al., 2013). Three categories emerged as a result of this iterative and interactive process (Malik, McKenna & Griffiths, 2018). The categories were raised to an abstract level where relationships between the categories resulted in a theory (Malik, McKenna & Griffiths, 2018).

Table 3: Audit trail for the category 'Reflecting on the event – after the encounter'

Examples of raw data	Coding	Subcategories	Category
"Up until then (MET review) I was cruisy, accepting every day as it come. After that I lost my confidence and I panic more now when I have trouble breathing..."	Coming to terms with new self-awareness	Experiencing an impact	Reflecting on the event – after the MET encounter
"It has made me more aware and I ask the nurses all the time to check my stats, when they do and they are ok I feel reassured."	Being made aware		
"It's opened up my eyes to how serious things are, how serious my breathing is, to the extent that I have started to see a psychologist here."	Realising the seriousness		
"It made me realise I am sick...and how precious life is."	Realising life is precious		
"They tend to disperse...they don't answer any questions, they are ready to move on"	Asking questions	Seeking an understanding	
"I think that after the MET call they tend to disperse and you want to know what happened but they don't answer any questions, they are ready to move on..."	Wanting to know what happened		
"When you're in situations like that you don't know what is going to happen but you've just got to accept it, can't do nothing about it."	Accepting what happened	Accepting of events	
"I have been deteriorating lately. I accept that and I accept what happened (the MET review). It's not often that I accept things like that."	Learning to accept		
"I have accepted a lot of things along the way and I know what's going to happen and all of that when a MET is called."	Accepting what has and will happen		
"...there was only one point, they were so busy talking about me they didn't pay attention to me...I was throwing up [vomiting] and all I wanted was a tissue."	Wanting to be seen	Wanting to be seen	
"...mustn't lose sight of the fact that the patient is actually a real person that doesn't have their knowledge and their expertise."	Losing sight of the person in the bed		
"...recognise that even though the patient can't articulate, that they are still in there and listening..."	Wanting to be seen		
"They (MET) are here to help you and make you comfortable, so just go with the flow."	Advising to go with the flow	Advising others	
"...go with the flow, be guided by them, they are the professionals..."	Being guided by professionals		
"Just take the advice, let them do their job..."	Taking advice		
"Don't hang about at home for too long. I mucked around a bit about whether I should have come in or not and I should have. Definitely come in quicker."	Advising not to hang about Being indecisive		
"Do not hesitate...if you're feeling a bit strange, ring your bell, tell your nurse. I should have the first time..."	Advising not to hesitate		
"Try to keep yourself positive as much as possible. Remember that your body may be sick but your brain is not."	Advising to keep positive		

3.4 Rigour and trustworthiness

The constructivist approach proposed by Charmaz (2006: 2014) places emphasis on the application of evaluation criteria in accordance with the purposes and context of the study. Charmaz (2014) suggests that originality and credibility increase usefulness, resonance and the value of the contribution. Therefore, the criteria of credibility, originality, resonance and usefulness were used to demonstrate the trustworthiness of this study. To enhance methodological rigour, interview transcripts were read and analysed repeatedly, constant comparative analysis of the data occurred, engaging in extensive memo writing, maintaining a reflective diary, writing field notes, and any pre-conceived ideas or assumptions the researchers had were acknowledged and not imposed on the findings (Charmaz, 2014). Some interviews were subject to member checking, a technique used to confirm that interpretations align with participants' meanings and experiences (Wong, Liamputtong, Koch & Rawson, 2017). Furthermore, two participants were contacted to verify that the theory reflected a true interpretation of their meanings. Interpretations of the study findings were supported by the research team.

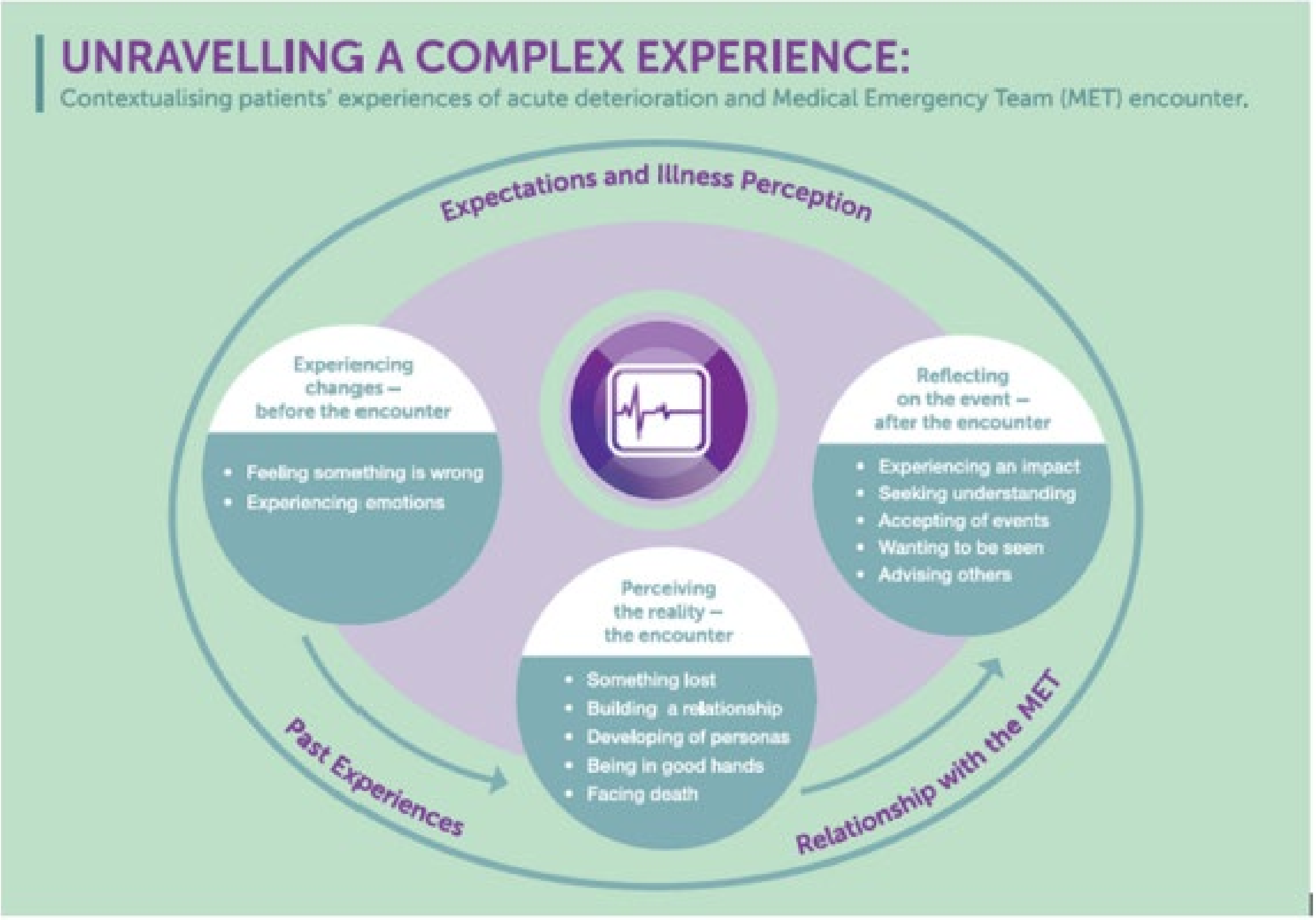
3.5 Ethical Considerations

Permission to conduct this study was granted by the human ethics committees of [redacted]. Potential participants were approached in accordance with hospital ethical requirements and written consent obtained. At each stage of the research process participants' anonymity and confidentiality was maintained and pseudonyms are used to present findings in this paper.

4. Results

The theoretical model entitled "Unravelling a complex experience: Contextualising patients' experiences of acute deterioration and MET encounter" emerged. The model describes patients' actions, processes and interplays with the clinical environment when experiencing acute deterioration and MET encounter. In the beginning, most patients began their journeys by recognising the onset of their own acute deterioration. For many, this insight and understanding triggered emotional changes such as fear and anxiety. For all, a combination of physical and emotional changes resulted in a MET encounter. Using the rich descriptions provided by study participants, we identified the following main components of this process: *Experiencing changes-before the encounter; Perceiving the reality-the encounter;* and *Reflecting on the event-after the encounter*. However, several contextual conditions were found to influence these processes, including; *expectations and illness perceptions, relationship with the MET* and *past experiences*. The theoretical model (Diagram 1) represents the relationship between categories and the contextual conditions that influence each. Each category is discussed below.

Diagram 1: Theoretical Model



4.1 Experiencing changes – before the event

The category, *experiencing changes – before the encounter*, represents participants' experiences of acute deterioration. The key activities they engaged were closely associated with the meanings they constructed around understanding their symptoms and their severity. This category is further conceptualised through sub-categories: *feeling something is wrong* and *experiencing emotions*. Most participants were involved in the process of *feeling something was wrong* which involved recognising and interpreting physical signals warning them of potential danger. Angela explained: *"…I woke up and the antiemetics had worn off and the pain relief had worn off, and I was just like shocked. Not with it, crying, in a lot of pain and not being able to breathe properly."*

In the beginning, several patients recognised the onset of their own acute deterioration and tended to experience physical symptoms such as feeling *'pain'*, *'nausea'*, *'aches'*, *'breathless'*, *'hot'*, *'cold'*, *'clammy'*, and *'dizzy'*. Amber explained: *"I started to get quite a bit of pain in my side, feeling very unwell…I can remember screaming in pain."* Enduring the physical symptoms of acute deterioration caused most participants to engage in the process of interpreting their own physical signs that warned them of potential danger. Terry stated: *"I was feeling so terrible, I couldn't breathe, and I had pain everywhere. I was scared and feeling anxious…"* The recognition and interpretation of physical symptoms caused participants to experience psychological responses in the form of fear and anxiety. Alex explained: *"When you can't breathe it's the most frightening thing…I was panicking so much."* Sam claimed *"I've never experienced this feeling ever before. It was horrific. It was so scary."* He qualified this by explaining that this feeling would remain with him, *"It's just something…I knew the way I felt, that I was finished…The feeling's going to be with me forever…I've experienced nothing like it before. It was scary and horrifying."*

For most participants, interpreting their physical signals involved the assessment of symptom severity, which in turn involved seeking help from their bedside nurse or calling an ambulance. For some, assessing the severity of their symptoms involved deciding whether or not the pain or discomfort they felt was worth calling for help. For example, Henry found it difficult, while as an inpatient, to interpret his deteriorating condition and call for help:

> *The nurse said, "You're not looking real crash hot". After around about half one I couldn't get back to sleep and realised that my breathing was getting much shallower and very crackly…[but] I waited for the nurse to come back and check on me which was about 3.30.*

For some, recognition of acute deterioration led to *emotional changes* that was beyond those experienced in everyday life, making it difficult for them to understand. Sam stated: *"I've* *never experienced this feeling ever before. It was horrific. It was so scary."* It was through these emotions that individuals construed various aspects of their experience. Participants, then, reacted to various stimuli in their environment depending on their response. Kelly said: *"I was a bit scared and uncertain about what was going to happen. Quite shocked because I was coming in for a simple procedure."* Therefore, depending on the emotional changes a participant had, it influenced their experience across other subsequent stages (categories). Consequently, participants' experiences of acute deterioration varied.

4.2 Perceiving the reality – the encounter

The category conceptualised as *perceiving the reality* represents the thoughts, emotions and sensations, which pass through a lens of the participants' conditioning and create their perceptions of the world. Therefore, there is always a possibility of multiple, and even competing, perspectives of the phenomenon in a highly complex social world (Singh & Estefan, 2018; Charmaz, 2014). Each participant shared their own reality within the highly complex world of acute deterioration and MET encounter. The category, *Perceiving the Reality – the MET encounter,* is further conceptualised through sub-categories: *something lost, building a relationship; developing personas; being in good hands*; and *Facing death*. The second category of patients' journeys was closely connected with the first; their acute deterioration resulted in a MET encounter.

Participants' recollections varied from no memories to vivid recall of events. Some participants had no recall of their MET review: *"I don't know what happened, I really can't remember a lot of what went on."* (Tara); *"I can remember screaming in pain and then I don't remember anything else."* (Amber); *"I don't have any recollection from the time everyone came in."* (George). Although some had limited or no recall of their MET review, what they did recall was of significance to them.

Participants relayed that their levels of satisfaction, comfort, and coping were dependent upon the relationship formed with members of the MET responsible for their care. The first meeting between participants and members of the MET had an impact on participants' experiences. David said: *"This is my first time in hospital so when I see a lot of doctors around me…about six or seven people…I just think, what is going on with me, I don't know what has gone wrong"*. In his first meeting with the MET, James discussed the number of health care professionals present, explaining: *"I was feeling pretty hot and the next thing I look around and there's people all over me…maybe eight people…they just attacked me."* Several participants interviewed also described feeling 'attacked', 'surrounded' or 'invaded' by the MET, Henry said:

> *No one really talked to me…In normal circumstances, you would have to say physically you feel invaded. But I was feeling so ill that I left myself completely open to the mechanics and said 'well whatever is going to be is going to be'…*

As interpreted by participants, qualities of a 'good' MET involved providing good care in a hurry, providing comfort, support and reassurance, being an advocate for the patient when they were too physically and emotionally weak to do so, keeping the participant informed, showing compassion and empathy, being efficient, and knowing what the patient needed. Kelly explained:

> *They were really good, they were explaining to me what they were going to do…the entire team was communicating with me and then they would communicate with each other, everyone knew what was happening…I was quite shocked because I was coming in for a small procedure but I felt secure because of how quickly they came to help me.*

Whereas, a 'bad' MET or negative experience, as delineated by participants, related to being disorganised, not attending the participant in a timely manner, losing sight of the person in the bed, not being attuned to the patient's needs, poor communication, not being informed and causing the pain. Angela said: *"…more and more people kept rocking up…I was having to repeat the same thing, I was in so much pain…I kind of felt like they talked down to me and they were disorganised."*

The term 'persona' refers to a mask or shield which a person places between themselves and people around them to conceal their true nature (Jung, 1953). This represents different personas or masks individuals assumed while being cared for during their MET encounter; many participants to some degree commented on the persona they adopted. Two main personas emerged: recipient and consumer. The consumer persona was typically chosen by the participant, whereas recipient persona was assigned by the MET. Characteristics of the recipient persona included the following terms: "do not interfere" (Henry and James), "passive" (Rose, June, Sam and Julie), "loss of control" (Rose and Tim), "did not ask questions" (Daniel, James and Sam), "compliant" (Sarah, Anna and Alex), "did not complain" (Angela) and "dependent" (Jill and Sarah). The characteristics of the consumer persona included the following descriptors: active, advocate, in control, assertive, helper, information seeker, want to be equal partner with medical professionals, demanding, and independent. David said: *"If I don't understand, I always ask them again until I understand the answer…remember that your body may be sick, but your brain is not."*

Many participants perceived they were 'in good hands' with their MET. Participants used various terms to qualify their perceptions of being 'in good hands': 'trust', 'confidence', 'well trained', and 'safe.' Being 'in good hands' was commonly described as having trust and confidence in the MET's abilities to care for them and save their lives. Paula explained: *"I trusted that I would be well looked after by the team…when I told them I was having trouble, they just leapt straight into* became more aware of their mortality as a result of their acute clinical deterioration and MET review. Sarah said:

> *I have to be thinking more about what I need to do and preparations that I really do need to have…I'd been facing up to things for a while, but that MET call was something that puts things (morality and death) more in front of me.*

When reflecting on the event, many participants questioned what had occurred. They did not know what happened, what was done and why or they were told some information after their MET review by their bedside nurse. Tara said: *"the nurse told me bits and pieces, but the others (MET) just sort of went."* Beth stated: *"they tend to disperse…they don't answer any questions, they are ready to move on"*. Vera said: *"I think that after the MET call they tend to disperse and you want to know what happened, but they don't answer any questions, they are ready to move on…"* Seeking understandings and participants being left with unanswered questions commonly occurred.

When on a journey to acceptance, participants had to work through a range of emotions. For some, the emotions they experienced such as uncertainty, fear and anxiety made it challenging for them to move past what had occurred. Even though participants commonly experienced these emotions throughout their acute deterioration and MET encounter, they were intensified after the event and on reflection. Vera, for example, explained that as a result of her MET encounter her anxiety had intensified: "…Up until then (MET encounter) I was cruisy, accepting every day as it came. After that I lost my confidence and I panic more…" Once participants worked through these emotions they were able to experience some form of acceptance: "I'm handling it pretty well. With everything that's been going on…I have accepted a lot of things along the way and I know what's going to happen and all of that when a MET is called." (James).

Many participants noted that the MET's focus was on their physical symptoms. On reflection, participants acknowledged that important aspects of their emotional and social selves were not attended to, individuals' illnesses become their defining features. Amber said: *"someone did say to me, oh…you are going to be alright but that was all."* Angela stated: *"…there was only one point, they were so busy talking about me they didn't pay attention to me…I was throwing up [vomiting] and all I wanted was a tissue."* Participants discussed the importance of 'being seen as a person' and the MET's failure to 'see the person in the patient' was deeply felt by individuals (Goodrich and Cornwell, 2008). Rose suggested that the MET: *"…mustn't lose sight of the fact that the patient is actually a real person that doesn't have their knowledge and their expertise."*

Participants discussed the importance of 'going with the flow' as they were unable to control aspects of their experiences and therefore, many suggested that patients faced with the same situation as theirs need to adopt a passive approach. Vera said: "*they (MET) are here to help you and make you comfortable, so just go with the flow.*" Beth suggested: "*There are a lot of people around and you have to go with the flow, be guided by them, they are the professionals.*" Many participants discussed the importance of listening to the MET to help with their fear and feelings of being overwhelmed. Margaret said: "*look it is overwhelming but listen to what they are saying…if you listen to them and not go into fear, they will help you through the stress.*" Trudy said: "*just take the advice, let them do their job, take their advice.*"

4.4 Contextual Determinants

From the data, several contextual conditions emerged influencing patients' experiences of acute deterioration and being cared for during MET review. Factors which were found to be influential are categorised into three broad areas: (i) *expectations and illness perception*, (ii) *relationship with the MET* and (iii) *past experiences*. These factors exerted a significant influence on participants' experiences and helps to explain the differences between them. Some participants identified that their acute deterioration and subsequent MET encounter was unexpected, and they perceived the nature of their illness (before their acute deterioration) as stable based on what they had been told by medical staff (*expectations and illness perception*). Many acknowledged that their experience was dependent on the health care professionals who were caring for them at the time (*relationship with the MET)*. Past experiences of illness and hospitalisation played an important role in participants ability to conceptualise their experiences of acute deterioration and MET encounter (*past experiences*).

5. Discussion

The initial phase of *unravelling a complex experience* reflects patients' interpretations of their physical and emotional changes. In most situations, it was the patient who recognised their own acute deterioration which triggered the escalation of their care. Even those who were initially ambivalent to their symptoms understood the seriousness of their condition once recognised by their bedside nurse. When *unravelling a complex experience,* we found participants commonly highlighted *feeling something is wrong* and generally were the first to recognise their own ominous signs. Although, some patients struggled to articulate their specific concerns, this has been identified in other studies (Odell, Gerber, & Gager, 2009; Doherty & Stavropoulou, 2012; Davis, Goldstein, Lawton, & Tagg, 2015; Guinane et al., 2018; Dwyer, Flenady, Khal, & Quinney, 2019; [redacted] [redacted]).

Once clinicians recognised the patient was clinically unstable and at risk of an adverse event, they escalated their care to a team of experts by triggering a MET review. In the next phase of the theory, patients encountered a divergent of experiences, perspectives and expectations while being promptly assessed and managed by members of the MET. Patients are required to build relationships with members of the MET while coping with physical and emotional changes. The relationships patients had with members of the MET were a central influence on their overall experiences. In a critical review and synthesis of qualitative research, Cutler et al., (2013) included 26 primary studies on patient experiences of critical illness. The researchers reported that for some patients, the relationships they had with healthcare professionals had a deep personal meaning which was described as the most interesting and useful theme to come from the review. According to Chipidza, Wallwork and Stern (2015), the healthcare professional-patient relationship is one of the most emotional and meaningful experiences shared by human beings.

International literature acknowledges that the healthcare professional-patient relationship directly influences health outcomes ([redacted]; Delaney, 2017; Chipidza, Wallwork & Stern., 2015; Sabater-Galindo et al., 2015; Doyle, Lennox, & Bell, 2012). In a Norwegian study, Strandas and Bondas (2017) conducted a meta-ethnography on the nurse-patient relationship (NPR). The authors acknowledged that the essence of the NPR was difficult to conceptualise but suggest that high-quality nursing depends on these relationships and is the foundation of nursing (Strandas and Bondas, 2017). The majority of the literature found reported on different elements of the healthcare professional-patient relationship, such as caring (Papastavrou, Efstathiou & Charalambous, 2011; Timmermann, Uhrenfeldt & Regner, 2015; Husanah et al., 2017), trust (Guassora & Gannik, 2010; Seifert, 2011; Hillen et al., 2012; Hillen et al., 2014; Qiu-Xia & Chen, 2018), respect (Richardson & Stanbrook, 2015; Clucas, 2016) and interpersonal interactions (Peplau, 2004). Relationships that were perceived as 'good' or 'beneficial' by patients encompassed these characteristics. The research suggests patients do not perceive all relationships as good (Strandas & Bondas, 2017). Uncaring relationships involve patients experiencing unnecessary suffering at the hands of healthcare professionals and feeling like an object instead of a person to be cared for (Halldorsdottir & Hamrin, 1997; Kasen, 2002; Eriksson, 2010; Strandas & Bondas, 2017).

The third category of *unravelling a complex experience*, focuses on the aftermath of the MET encounter and patients' reflections of the event. In line with a previous study conducted by Cutler et al. (2013) on patient experiences of critical illness, our theory asserts that understanding an experience does not rely on factually accurate recall of the event (Cutler et al., 2013). Some argue that "personal meaning is not objective or rational but contextual and individual" (Cutler., 2013, p.156). Participants in this current study constructed a hierarchy of need, where some patients' need for knowledge and understanding about their illness were of great importance, whereas others were less reflective and felt they could manage without further understanding.

Many participants offered advice to other patients in similar situations and to healthcare professional caring for them. Participants advised patients to not delay seeking help, to think positively, to hang in there and to look after their health, while they advised healthcare professionals to see the person in the bed, instead of focusing on tasks. Recognising that the way a patient is treated as a person is central to high quality care (Department of Health 2008a; Maxwell 1992). Recently, policymakers and health care organisations have made exploring patients' experiences of healthcare a national priority as it provides an important insight into care quality (Jones, Vaux, & Olsson-Brown 2019; Goodrich & Cornwell, 2008). In a review paper on patients' experiences of healthcare, Goodrich and Cornwell (2008) suggest improving patient experiences is not only justified clinically but also economically. For example, evidence from clinical studies suggest that when a patient experiences a negative psychological response such as anxiety and fear, it can delay healing causing longer hospital stays (Goodrich & Cornwell, 2008; Cole-king & Harding, 2001; Norman, 2003; Weinman, Ebrecht, Scott, Walburn, & Dyson 2008). Research also suggests that if a patient experiences good communication, it contributes positively to their overall wellbeing and hastens recovery (Bauman, Fardy, & Harris, 2003; Shuldham 1999; Suchman 1993; Boore, 1978).

The constructed theory offers an understanding into patients' journeys of striving to understand their experiences. Each process within the journey is closely linked and influences each other, which is illustrated through a unique theoretical model. To date, no such study has been undertaken in Australia and therefore, is the first to describe the phenomenon. Findings provide an explanatory framework for similar phenomena and increases awareness of patients' experiences to ultimately inform health policy and improve patient care. The emergent theory leads to recommendations that healthcare organisations gather data about patients' experiences of acute deterioration and MET encounters, as these are valuable, relevant, meaningful and emotionally salient. The findings highlight the need for healthcare services to instigate strategies that support patients who have experienced acute deterioration. Further research could evaluate the effectiveness of implemented strategies.

6. Limitations

Patients were interviewed from Australian hospitals only, therefore the constructed theory may not be transferable to different settings. Also, the experiences of family members, nursing staff, medical staff, or members of the MET team were not explored which may add richness to the study findings.

7. Conclusion

This study has taken a unique approach in presenting a theoretical construct, *unravelling a complex experience: endeavouring to contextualise patients' experiences of acute deterioration and MET encounter*, that provides insight into social processes of patients' experiences of acute deterioration and being cared for during a MET review. Our theory provides a framework for explaining similar phenomena and raises awareness of patients' experiences which can improve patient care. The research highlights the need for healthcare professionals to respond with confidence and compassion when caring for an acutely deteriorating patient. Furthermore, our theory could be a valuable framework for exploring patients' experiences of other clinical events.

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6.2 Summary of Chapter Six

In the preceding chapter, the three major categories which are embedded in the theoretical model were presented. In Chapter Six, the grounded theory and the related theoretical model which were developed as a result of constant engagement with an iterative process of data analysis, were discussed. Although it cannot be generalised, this theory offers an abstract understanding of patients' experiences of acute deterioration and MET encounter. The theory also highlights variations in data which reflects the contextual conditions accountable to varying experiences, analysed through interview transcripts. Chapter Seven explores the contextual determinants impacting on patients' experiences.

CHAPTER SEVEN

Contextual Conditions

Chapter Seven: Contextual Determinants

7.1 Introduction

In the preceding chapter, the theory '*Unravelling a complex experience: contextualising patients' experiences of acute clinical deterioration and MET encounter*' was presented. This chapter offers insights into how the experience of acute deterioration and being cared for during a MET review differs depending on certain contextual factors. These contextual conditions mediated participants' actions and behaviours towards the key research problem and were categorised into three broad groups:

1. Expectations and illness perception
2. Relationship with the MET
3. Past experiences.

These factors are not within the participant's control, they are externally imposed and occur by chance. The properties of contextual conditions were viewed by participants as essential mediators of their satisfaction, coping, and comfort. Although, some grounded theorists question the analysis of data to determine contextual conditions influencing the theory (Birks & Mills, 2015), Charmaz (2014) emphasises the significance of relating process into its context by arguing "situating grounded theories in their social, historical, local and interactional contexts strengths them" (p. 322). This chapter comprises one manuscript, which is currently under review for publication in the Journal of Advanced Nursing (Submitted Feb 2021).

Paper 3

Chung, C., McKenna, L., Cooper, S.J. (Under Review). Contextual factors influencing patients' experiences of acute clinical deterioration and Medical Emergency Team (MET) encounter: A grounded theory study. *Journal of Advanced Nursing* (Submitted in Feb 2021).

Contextual factors influencing patients' experiences of acute clinical deterioration and Medical Emergency Team (MET) encounter: A grounded theory study

Abstract

Aim: This paper focuses on personal, social and structural factors that influence patients' experiences of acute deterioration and medical emergency team (MET) encounter.

Background: Patient experience is recognised as a means of assessing healthcare delivery with a positive experience being linked to high quality healthcare, improved patient safety and reduced length of stay. The experience of acute deterioration is unique, extensive and complex. However, little is known about this experience from the patient's perspective.

Design: Constructivist grounded theory, informed by Kathy Charmaz was used to explore the personal, social and structural factors that influence patients' experiences of acute deterioration and MET encounter.

Methods: Using a semi-structured interview guide, in-depth individual interviews were conducted with 27 patients from three healthcare services in Victoria, Australia. Data were collected over a 12-month period in 2018-2019. Interview data was analysed using grounded theory processes.

Findings: Contextual factors exert a powerful influence on patients' experiences of acute deterioration and MET encounter. The most significant factors identified include expectations and illness perception, relationship with the MET and past experiences. The expectations and perceptions patients had about their disease can condition their overall experience. Healthcare professional-patient interactions can significantly impact quality of care, patient experience and recovery. Patients' experiences of illness and health care can impact a person's future health seeking behaviour and health status.

Conclusion: Patients' actions and processes regarding their experiences of acute deterioration and MET encounter are the result of the complex interface of contextual factors.

1. Introduction

Patient experience is recognised as a means of assessing healthcare delivery with a positive experience being linked to high quality healthcare, improved patient safety and reduced length of stay. The experience of acute deterioration has been described as unique, extensive and complex ([redacted]), however, little is known about this experience from the perspective of the patient. Studies exploring the contextual factors that influence patients' experiences of health care has gathered momentum over recent years, however, the contextual factors that influence patients' experiences of critical illness, including acute deterioration and MET encounter has received little attention. An in-depth understanding of these contextual factors creates opportunities for health care services to implement strategies to improve patient experiences.

2. Background

Health care services are treating increasing numbers of patients with complex medical conditions who are vulnerable to rapid physiological deterioration ([redacted]; Guinane et al., 2018; Buykx et al., 2012; Schoen et al., 2009). Clinical deterioration is defined as a serious physiologic disturbance or a sudden worsening of patient physiological condition (Al-Moteri et al., 2019). Over the past decade, patient safety and ensuring patients who experience acute deterioration receive appropriate and timely care, has been a global concern ([redacted]; Australian Commission of Safety and Quality in Health Care [ACSQHC], 2017). As defined by the World Health Organisation (WHO), patient safety is "the prevention of errors and adverse effects to patients with health care" (WHO, 2015). Despite growing evidence suggesting health care professionals are well equipped to address the needs of deteriorating patients, major gaps remain in our understanding of patients' experiences of acute clinical deterioration and MET encounter. Research suggests that patients are sensitive to, and able to, recognise a range of issues in health care delivery (Ricci-Cabello, Avery, Reeves et al., 2016; Schwappach, 2010) that may not be identified by other systems of health care monitoring (Ricci-Cabello, Avery, Reeves et al., 2016; Levtzion-Korach, Frankel, Alcalai et al., 2010). In the current literature, the absence of the patient's voice is particularly pertinent in the current rhetoric of quality improvement and safety ([redacted]; Guinane et al., 2018; Kenward et al., 2017).

The role that contextual factors play in shaping patients' experiences of acute deterioration and MET encounter has begun to receive some attention from researchers. For example, Strickland, Pirret and Takerei (2018) identified a link between patients' experiences of acute deterioration and their knowledge of their illness and symptom recognition. Yet, despite their ideological connection, factors such as expectations and illness perception, relationship with members of the MET and past experiences all moderate patients' behaviour towards conceptualising their experiences. There is a body of work starting to emerge, however, none of the literature explicitly documents the influence of contextual factors on patients' experiences of acute deterioration and MET encounter. While contextual factors do not determine behaviours and attitudes, they do have a significant impact upon patients' experiences (Hall, McKenna & Griffith, 2013).

3. Aim

As part of a larger study designed to understand patients' experiences of acute deterioration and MET encounter, this paper focuses specifically on the contextual factors that influence patients' behaviour and attitudes when experiencing acute deterioration and MET encounter.

4. Design

The consolidated criteria for reporting qualitative research (COREQ) checklist was applied to enhance quality and transparency of this study (Tong, Sainsbury & Craig, 2007). Constructivist grounded theory (CGT) was chosen to explore patients' experiences of acute deterioration and MET encounter. The research was underpinned by the theoretical assumptions of symbolic interactionism, which assumes individuals construct selves, society, and reality through interaction (Charmaz, 2014; Hall, McKenna & Griffith, 2013). CGT places emphasis on processes and actions relating to particular situations, constructed between participants and researcher (Charmaz, 2014). Therefore, the findings became a co-construction of the researcher's interpretation of the data and participants' experiences (Charmaz, 2014).

4.1 Data Collection

Purposive sampling was used to recruit participants and theoretical sampling was employed to focus on important concepts. Demographic characteristics of participants are presented in Table 1. Hospital patients over 18 years of age who experienced acute clinical deterioration resulting in a MET review were invited to participate in the study. The exclusion criteria were patients who were confused and/or unable to provide informed consent, assessed as clinically unstable by a hospital clinician, obstetric patients, patients who had an active complaint against the hospital and patients admitted to a mental health unit or under a mental health team. An explanatory statement and consent form was distributed and interested participants were followed up by the researcher and consented to be interviewed. Twenty-seven patients were interviewed until emerging categories were saturated. Participants were interviewed one-on-one while in hospital, at a mutually agreed time for approximately 30 minutes, using a semi-structured format with some guiding questions. Interviews were audio-recorded, with permission from participants, and subsequently transcribed.

4.2 Ethical Considerations

Permission to conduct this study was granted by the human ethics committees of Monash University (12571), Federation University Australia (E18-003) and the relevant healthcare services (1347, HREC/19/BHSSJOG/20, 2018-05). Potential participants were approached in accordance with hospital ethical requirements and written consent obtained. All participants were assigned a pseudonym to protect their identity.

4.3 Data Analysis

In keeping with the tenets of grounded theory, data collection and analysis occurred simultaneously. Data generated from interviews were analysed using initial, focused and theoretical coding (Charmaz, 2006; 2014). Preliminary subcategories and categories were constructed from the coding process and were constantly compared with codes, and emerging concepts to reveal actions, processes and events (Charmaz, 2014). Theoretical sampling and memoing supported concept development to establish properties of categories and relationships between each. By engaging with an iterative and interactive method, the advanced stage of coding resulted in three categories and a core category. Contextual factors identified within categories included: *expectations and illness perception*, *relationship with the MET* and *past experiences*, which are the focus of this paper.

4.4 Rigour and trustworthiness

The evaluation criteria of credibility, originality, resonance and usefulness proposed by Charmaz (2006; 2014) was used to ensure the trustworthiness of this study. Methodological rigour was enhanced by constant comparative analysis of the data, engaging in extensive memo writing, maintaining a reflective diary, writing field notes, and any pre-conceived ideas or assumptions the researchers had were acknowledged and not imposed on the findings (Charmaz, 2014). Interview transcripts were read and analysed repeatedly and some were subject to member checking. Additionally, two participants were contacted to verify that the theory reflected a true interpretation of their meanings and interpretations of the findings was supported by the research team.

5. Findings

A number of contextual factors mediated patients' experiences of acute deterioration and MET encounters. The factors that were found to be important are categorised into three broad areas: (i) expectations and illness perception, (ii) relationship with the MET and (iii) past experiences.

5.1 Expectations and illness perception

Data generated from interviews revealed that patients' illness expectations played an important part in their attitudes, beliefs and understanding of what occurred. Many participants identified that their acute deterioration and subsequent MET encounter was unexpected. One patient discussed being surprised by the event:

> *... I don't know how to describe it... it was just really quick. I mean didn't feel uncomfortable or anything. They were all asking, "Are you okay? Do you feel well?"...They were obviously making sure I was alright so... But to start with I was a little bit not stressed but surprised. I just didn't expect it ...* (June).

Being 'surprised' when experiencing acute deterioration and a MET encounter is an interpretation of a range of behaviours that patients often struggled to describe. Kelly talked about being scared, uncertain and shocked by her sudden clinical instability because she was admitted to hospital for what she described as a 'simple procedure':

> *... I was quite shocked because I was coming in for a simple procedure... I didn't know what the consequences were for my blood pressure dropping down. I think it dropped down to about 70 something which is very low and can be life threatening... I was a bit scared and uncertain about what was going to happen. (Kelly)*

Tara also described being shocked by her unexpected acute deterioration and MET encounter *"...when I woke up I couldn't figure out what all the fuss was about ... I was a bit shocked, I couldn't understand what had gone wrong."* She qualified this by explaining *"... I can remember there was no sense coming out of me ... and I couldn't work out what the heck was going on..." (Tara))*

In contrast, some participants were not surprised or shocked by their episode of acute deterioration and subsequent MET encounter. One participant, diagnosed with a terminal illness stated: *"I'm dying anyway"* (Anna) and although she was not surprised by her acute deterioration Anna described being tired and feeling emotional while discussing her resuscitation status with the MET:

> *When they talk about your own death, you do get a little emotional. But I'm not going to burst out crying or anything else like that because I've faced this three times. It's just sometimes saying it out loud...*(Anna)

Another participant, George, also talked about not being surprised by his acute deterioration and MET encounter because of the nature of his illness: *"...I've been through dozens of medical things ... but I wasn't surprised when my blood pressure dropped, death doesn't worry me..."* On reflection, George did not realise how unwell he was at the time of his acute deterioration: *"I started to realise only after I started to improve is when I realised how unwell I really was. I couldn't get out of bed I just was bedridden basically I didn't realise it at the time ..."* (George)

Some participants perceived the nature of their illness, before their experience of acute deterioration, as stable based on what they had been told by medical staff and their discharge plan, for instance:

> *...the doctor said that I would be okay in one day, so they sent me to short stay. I had been there one day and then I felt a bit better but when they checked my blood pressure, it was going down, settled at 50 something and then at that time, they changed me to the ICU (MET call) ... I am usually a healthy person and sporty person ... I also had been worried about my health because so many doctors came around me, asking lots of questions (David).*

> *I was about to go home. I was ready to walk out the door and they told me that I had funny blood test results. So they kept me and I started to slowly feel worse ... (Amber)*

Additionally, some participants did not raise issue with their symptoms of acute deterioration as they associated it with their illness expectations:

> *I felt a bit flat. I was a little bit dizzy but I thought that was because of the morphine, because I had morphine for the pain half an hour or an hour before ... I didn't think anything of it. It was just when they did my obs [vital signs], they realised that my blood pressure was really really low, which should not be that low... (Kelly).*

> *But they said, "No, this is really quite common after heart surgery or a surgery" ... So once I told myself it's common, I just laid back and relaxed, there was nothing I could do about it ... (Rose).*

5.2 Relationship with the MET

From the perspective of the participants in this study, many acknowledged that their experience depended on the health care professionals who were caring for them at the time of their acute deterioration and MET encounter. A number of participants identified members of the MET who they had valued during their review:

> *The nurse was being very forceful in what she was saying about my blood pressure being so high, she was making sure because she felt the doctor wasn't taking that into consideration.*

> *I know she reiterated that several times…I was grateful that she was doing that. I knew she was on my side. I don't know what I would have done without her. I really don't* (Sarah).

> *I thought they were marvellous, I wasn't up to doing anything much and they just took over, and I felt quite safe in their hands…they don't mess around, they've got your welfare at the back of their minds. You know, what's not to like about that?* (Rose).

Given the dependent and intimate nature of the MET-patient relationship, all participants noted that the personality and competence of the MET members was of significant importance as mediators of good and bad MET experiences. Participants often characterised the MET along the dimensions of good and bad. A variety of descriptors were used to characterise a 'good' MET: 'knowledgeable', 'good', 'were there is a hurry', 'efficient', 'provided comfort and reassuring', and 'took the time to explain.' The features of a 'bad' MET included: 'detached', 'rushed', 'delayed in arriving', 'disorganised', and 'did not explain.' Not all participants placed the same importance on each of these characteristics. For some participants, importance was placed on therapeutic communication rather than clinical competence. Joan described the MET as being: *"a beautifully structured team"* that *"even if you think you are on your last breath, you think, thank God you are in really good hands."* But for Joan this was not enough, she recalled the MET being: *"caught up in their stuff"* which caused her to be scared and overwhelmed.

For Sarah and Tara, they both experienced acute deterioration and MET review due to medication errors, administered by healthcare professionals. Both Sarah and Tara had negative experiences with their respective METs, relating to pain. Tara said, *"It was hurting my arm. I kept saying, 'Please don't do it anymore', but they kept on doing it…I suppose they had to but I didn't want them to touch me…" (Tara)*

Sarah also explained:

> *You can't do that. You're hurting me, you're hurting me. You have to take it out! I want you to take it out! He took it out and comes at me with another one and he says 'I have to put another one in'. I said, 'Do not come near me. (Sarah)*

For some participants, a negative experienced had a lasting effect. It caused a spectrum of feelings such as worry, helplessness, hopelessness and vulnerability:

> *I was frightened it would happen again and it made me question everything...I'd keep apologising, saying to the nurses, 'Look it's not you. It's just that I've had that bad experience'. I had to keep finding out what they were giving me, why and how much* (Tara).

5.3 Past Experiences

Data generated from interviews highlighted that participants' past experiences of illness and hospitalisation played an important role in their abilities to conceptualise their experiences of acute deterioration and MET encounters. For example, George's ailing chronic condition and previous near-death experiences led to a commitment to get better and live life to the fullest despite his condition:

> *I am determined to get better. I spent over two weeks or whatever in the hospital with a bacterial infection. I was sent home thinking I was alright but I never felt 100%, the next thing I was back in hospital with the same thing and I went through probably more because I had lost weight and my conditioning was right down. I was very vulnerable so I knew I wasn't in a good place when I had the MET call but I just accepted, yep I will get better.*
>
> *(George)*

Tara's previous experience of acute deterioration and MET review was due to a medication error by healthcare professionals. This previous experience influenced the trust she had for the current MET. Tara described how the development and maintenance of trust in healthcare professionals was ongoing, qualifying this by explaining:

> *I think the fact that I'd been overdosed in the past... I thought if they've got that wrong, what else could they get wrong? Once you've had a fright like that it doesn't leave you...I'd keep apologising, saying 'Look it's not you. It's just that I've had this bad experience, I've got to find out what you're giving me. Why you are giving me that drug? (Tara)*

Some participants who had a previous experience of hospitalisation measured the seriousness of their condition by the number of healthcare professionals present. Julie said, *"Something was going on, I knew something was badly wrong with me for so many people to be in the room."* This was similar to Alex who stated, *"Usually when I come there's a couple of people but this time I reckon there was eight or ten people."* Additionally, some patients who experienced acute deterioration and MET encounter more than once emphasised the fear that remained. Tim explained, *"It's still a bit scary, the second time. The number of doctors I had means I'm in trouble, if I have one or two, okay that'll be fine. But maybe it was like five or six nurses and doctors."* James said: *"The first time [MET review] is a bit scary, you don't know exactly what's going to happen…actually it doesn't get less scary."*

Overall, the interplay between expectations and illness perception, relationship with the MET and past experiences was evident. These factors played important roles in patients' abilities to conceptualise their experiences of acute deterioration and MET encounters.

6 Discussion

The study findings offer insights into contextual factors affecting patients' experiences of acute deterioration and MET encounters in Australia. The aim was to provide adequate detail to offer valuable insights into the influences of contextual factors on patients' experiences of acute deterioration and MET encounter, which may be transferable to similar settings.

The expectations and perceptions patients had about their illness trajectory had a significant impact on their experience. Patients' perceptions of their disease and expectations can condition their overall experience (Mazzotti, Sebastian & Marchetti., 2012). Health psychology research suggests that under certain conditions, health behaviours are influenced by patient-perceived severity and is considered a substitute for beliefs about the objective controllability of disease (Mazzotti, Sebastian & Marchetti., 2012; Albarracin, Gillette, Earl et al., 2005). According to the health belief model (Hochbaum, 1958), patients' perceptions and actions will change when disease severity and perceived vulnerability combine to form a "threat." The extended parallel process model (Witte, 1992) suggests, that healthy behaviours occur if there is a balance between threat and efficacy beliefs (Mazzotti, Sebastian & Marchetti., 2012).

The relationship patients had with members of the MET in this study had a significant impact on their experience. Our results are consistent with other research that suggest the healthcare professional-patient interaction can have a significant impact on quality of care, patient experience and recovery (Mylen et al., 2016; Alpers et al., 2012; Cypress, 2011). A recently published Norwegian study found that the quality of the nurse–patient relationship for example, strengthens not only health but also the patient's own resources for health and well-being (Strandas and Bondas, 2017). We found that "relationships" were raised as important aspects of personal meaning for participants and exerted a significant influence. All participants were affected by the interaction they had with members of the MET to some extent. Our findings are in accordance with international research that indicates that the nurse-patient relationship/healthcare professional-patient relationship is one of the most important aspects for successful treatments (Molin, Graneheim, & Lindgren, 2016; Peplau, 2004).

Patient reported outcomes measures (PROMs) and patient reported experience measures (PREMs) provides a means of exploring the relationship between patient safety, clinical effectiveness and patient experience when being cared for in hospital (Kingsley & Patel, 2017; Black, Varaganum & Hutchings, 2014). Some studies have explored the relationship between PROMs and PREMs with hospital patients and found that patients admitted following an acute event reported good communication by clinicians was associated with better post-discharge health related quality of life (HRQL) and better physical health (Larson, Nelson, Gustafson et al., 1996; Fremont, Cleary, Hargreaves., 2001). Whereas, patients who were admitted with a chronic condition, such as chronic obstructive pulmonary disease and diabetes, reported good health outcomes if they had a positive experience and better mental health associated with greater trust in the doctor and support for self-management (Black, Varaganum & Hutchings, 2014; Slatore, Cecere, Reinke et al., 2010). No studies were found that specifically explored the relationship between PROMs and PREMS with hospital patients who had experienced acute clinical deterioration and MET encounter suggesting further research is necessary.

In this study, we found that patients' experiences of illness and hospitalisation formed an important part of the contextual factors. It is well documented in the literature that experiences of health care can impact a person's future health seeking behaviour and health status (Schwei et al., 2016; Eriksson and Svedlund, 2007; Bankauskaite and Saarelma, 2003). For example, a negative experience can result in the avoidance of or delays in seeking further health care (Schwei et al., 2016; Eriksson and Svedlund, 2007;) and distrust or suspicion of the health care system (Suurmond, Uiters et al., 2011; Martins, 2003; Nickasch and Marnocha, 2009). In a Swedish study, Eriksson and Svedlund (2007) explored hospital patients' experiences of dissatisfaction with care. The authors found that patients who were dissatisfied by the care they received during a previous healthcare experience were more likely to wait too long before consulting a healthcare professional and feel guilty for partly causing the issue themselves. These findings are in accordance with our study that recognises patients' behaviours and expectations differ depending on their experiences of health care.

Patients participating in our study have highlighted the need for both screening policies and practical management for patients who experience acute deterioration and MET encounter. It is concerning that survivors of acute clinical deterioration may experiencing perceptual, emotional and physical distress that could go unnoticed by health care providers. By being informed, clinicians will be better equipped to provide support to reduce external causes of anxiety for patients.

7 Limitations

While this study offers an in-depth analysis, the theory has been constructed from data derived from a group of patients from Australian hospitals and therefore may not be directly transferable to different settings. Also, the experiences of family members, nursing staff, medical staff, or members of the MET team were not explored which may add richness to the study findings.

8 Conclusion

Patient experience is a pivotal component in measuring healthcare quality. Patients' experiences of acute deterioration and MET encounters involve highly complex processes. While their views are often accepting of what occurred, contextual conditions play an important role in mediating their actions and understanding. Patients' experiences are the result of the interface between expectations and illness perception, relationship with the MET and past experiences. The findings invite healthcare services to adopt screening policies and practical management for patients who experience acute deterioration and a MET review.

Conflict of Interest

None.

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7.2 Summary of Chapter Seven

Contextual factors found to be influential on patients' experiences of acute deterioration and MET encounter were explored in Chapter Seven. The chapter comprised one manuscript submitted for publication, exploring these factors in three broad areas: (1) Expectations and illness perception, (2) Relationship with the MET, and (3) Past experiences. Explication of these factors facilitates an understanding of participants' actions and behaviours in various contexts, which requires measures to enhance facilitators and surmount barriers. In the next chapter, analysis of the findings considering the global literature, along with educational and practice recommendations are discussed in greater length.

CHAPTER EIGHT

Discussion and Recommendations

Chapter Eight: Discussion and Recommendations

8.1 Introduction

The preceding chapters have highlighted the challenges faced by patients when experiencing acute deterioration and MET encounter. The findings pose significant meaning for clinical practice as they raise several issues for patient care. Chapter Eight provides an overall discussion of the findings and situates the results within the existing literature. This chapter also highlights new knowledge developed in the absence of available research in the context of patients' experiences of acute deterioration and MET encounter. The implications and recommendations for education, practice and research are presented. This chapter begins with an overview of the theory and discusses the key findings considering the global literature.

8.2 The Theory

The theoretical construct, *Unravelling a complex world: contextualising patients' experiences of acute deterioration and medical emergency team (MET) encounter,* forms the central element of the research. It offers an explanation of the specific processes adopted by patients when experiencing acute deterioration and a MET review. Additionally, this theory offers a comprehensive understanding of conceptual links and interplay between the defined categories, *Experiencing Changes – before the encounter*, *Perceiving the Reality – the encounter* and *Reflecting on the Event – after the encounter*. Within the categories, all salient properties and dimensions have been identified, ensuring explanatory power of the theory. For instance, in the category, *Perceiving the Reality – the encounter*, participants demonstrated passion towards the relationship they had with members of the MET, it was a central influence on their experience. Participants relayed that their level of satisfaction, comfort, and coping was dependent upon the relationship formed with members of the MET responsible for their care. The various properties of the theory explain processes which could be applied to patients in similar contexts, as it highlights the challenges they encountered and strategies adopted to overcome them.

8.2.1 The Beginning - Experiencing Acute Deterioration

The findings from the first category, *Experiencing changes – before the encounter,* draw attention to differences in participants' experiences of acute deterioration and what these meant to them. The key activities participants engaged with were closely associated with the meanings they constructed around understanding their own symptoms and interpreting the severity. Commonly, patients are astute at noticing the onset of physical symptoms but unable to interpret their clinical significance (Chung et al., 2020; Guinane et al., 2018; Rosa et al., 2017; Strickland et al., 2019).

Participants in the present study may not have understood the severity of their acute deterioration, but typically knew they were unwell and require treatment. Cutler et al. (2013) conducted a critical review and synthesis of qualitative research on patient experiences of critical illness which included 26 primary studies. The authors suggest that events prior to the critical illness may be significant for patients, in the process of understanding their experiences (Cutler et al., 2013). They also highlight that critical illness, not only renders patients vulnerable on a physiological level, but also emotionally. It is of concern that the recognition of acute deterioration is largely based on the bedside nurse's understanding and interpretation of clinical signs. In an Australian study, Guinane et al. (2018) explored the experiences of 33 patients who received a Medical Emergency Team (MET) review following an episode of clinical deterioration. The authors reported that participants recognised the onset of physical symptoms associated with clinical deterioration, and that prompted them to inform their bedside nurse, although participants were unable to interpret the clinical significance of the symptoms they were experiencing. Participants in this study believed the interpretation of the symptoms was the responsibility of the healthcare professional (Guinane et al., 2018).

Internationally, track and trigger systems used by healthcare professionals to predict acute deterioration is well reported in the literature (Chung et al., 2020). However, recent studies suggest that, they are not always appropriately acted upon when patient deterioration is predicted (Currey et al., 2018; Gill et al., 2016; Quirke et al., 2011; Strickland et al., 2019). A New Zealand study conducted by Strickland et al., (2019) explored patients' and families' experiences of acute ward deterioration and their perceptions of a need for a patient and/or family activated escalation service. The authors found that when experiencing acute clinical deterioration, most patients understood their current illness and were able to discuss, in varying detail, what they thought was wrong with them (Strickland et al., 2019). This was based on the information provided to them by healthcare professionals, before their episode of deterioration. In this study, Strickland et al., (2019) also reported that the degree to which patients recognised their own deterioration varied from complete awareness to a vague sense that something was wrong. Some participants also expressed not knowing that their condition had deteriorated and were surprised when informed by nursing staff of their physiological deterioration (Strickland et al., 2019).

Concurring with the above studies, most participants in the current study were involved in the process of knowing something was wrong which involved recognising and interpreting physical signals warning them of potential danger. For most participants, this recognition and interpretation led to a psychological response that was beyond those experienced in everyday life, making it difficult for them to understand. The psychological impact of acute deterioration raises concerns for patients and their recovery (Chung et al., 2020). There is a growing body of evidence suggesting that patients continue to experience psychological distress such as depression, guilt, anxiety, hopelessness, fear, loneliness, isolation, despair, and irritation after their critical event and discharge (Chung et al., 2020; Cutler et al., 2013; Guinane et al., 2018). In addition, participants in the current study commonly described their acute situations as terrifying, threatening to their existence and shocking, chaotic and with ongoing feelings of anger (Chung et al., 2020). It was through these emotions that individuals construed various aspects of their experience. Participants, then, reacted to various stimuli in their environment depending on their response. Therefore, depending on the psychological response a participant had, it influenced their experience. Consequently, participants' experiences of acute deterioration varied. These findings coincide with the results from national and international studies (Corner et al., 2019; Cypress, 2011; Drenth, 2013; Hashem et al., 2016; Tembo et al., 2012), that reported similar when exploring patients' experiences of critical illness. In line with these studies, the present study findings contribute to the existing body of literature.

In an English study, Kean et al. (2016) aimed to theorise intensive care unit survivorship after a critical illness using a longitudinal qualitative design. The authors suggest that a sudden critical illness and admission to ICU constituted "an unscheduled status passage, symbolising the observable starting point of a person's transition from health or a stable chronically ill health state to critical illness" (Kean et al., 2016, p. 3116). While exploring critically ill and ventilator-treated patients' recollections at three- and 12-months following discharge from ICU, Loft et al., (2006) found that for most patients, their memories of becoming unwell before arriving at the ICU were profound and detailed, implying they had a deeply emotional experience. The authors suggest that critically ill patients often experience a state of emotional chaos which may begin before being admitted to ICU, leading to feelings of extreme instability, fear and dread (Loft et al., 2006). Concurring with the above studies, when experiencing acute deterioration participants in the current study described experiencing an array of emotions. It is of concern that the impact of experiencing acute deterioration is relatively unknown. Therefore, further studies are required to explore and fully understand the perceptual, emotional and physical impact acute deterioration has on patients, so appropriate strategies can be introduced to provide ongoing support.

8.2.2 Medical Emergency Team (MET) Encounter – The Challenges

The findings in this study demonstrate the challenges patients experience when being cared for by a MET. Some participants found it difficult making a connection with members of their MET. They expressed concern around being excluded, feeling overwhelmed, attached, surrounded or invaded. This was found to be associated with emotions such as frustration, vulnerability and fear, and a sense of ill ease at not being treated as a human being (Chung et al., 2020). Global studies exploring patients' relationships with healthcare professionals (nurses, physicians) have highlighted its importance although the essence of the relationship seems difficult to conceptualise (Berglund et al., 2016; Conroy et al 2017; Cutler et al., 2013; Strandas & Bondas, 2017). Much of the literature explores different elements of the relationship such as respect (Rasti & Jahanpour, 2014; Tingleff et al., 2017), caring (Papastavrou et al., 2011), interpersonal interactions (Fry-Bowers et al., 2014; Kreuzer et al., 2020; Williams & Irurita, 2004), and trust (Chandra, 2018; Norberg Boysen et al., 2018). Others aim to describe different types of relationships (Molina-Mula et al., 2020; Morse, 1991) or explore the relationship holistically (Zamanzadeh et al., 2015). The healthcare professional-patient relationship is one of the most moving and meaningful experiences shared by human beings (Chipidza et al., 2015). The current study participants described the relationship they had with members of the MET as essential to their care and a central influence on their experience.

A Swedish study conducted by Berglund et al. (2012) explored patients' experiences of care in the hospital setting, revealing feedback from 22 patients who experienced life-threatening and/or long-term diseases. Participants reported suffering caused by care when they felt mistreated, distrusted, or not listened to by healthcare professionals. Participants also described a negative relationship with health care professionals when their symptoms were ignored or not taken seriously. This lack of connection or rapport caused participants to feel increasingly vulnerable. Another study by Cypress (2014) aimed to understand the lived emergency department experiences of patients during critical illness. The author describes the patient-healthcare professional relationship as a collaboration where each person contributes towards achieving optimal and realistic goals. Communication was overwhelmingly identified by participants as an important component of the patient-healthcare professional collaboration to ensure safe and effective care (Cypress, 2014). Additionally, Dang et al. (2017), while investigating what patients saw as the most critical elements for building trust and rapport with healthcare professionals, found patients could experience increased psychological distress, ranging from feelings of vulnerability, to fears, situational anxiety and panic, especially when the condition is life-threatening (Dang et al., 2017). The authors suggest a key step in building a therapeutic relationship is for healthcare professionals to recognise that a one approach may not fit all as some patients may have greater emotional needs (Dang et al., 2017). In line with the above studies exploring patients' experiences of the nurse-healthcare professional relationship, the present study findings contribute to the existing body of literature. In particular, there were some identified challenges unique to the present study that impacted the relationship participants had with members of the MET, including the MET being disorganised, not attending the participant in a timely manner, losing sight of the person in the bed, not being attuned to the patient's needs, not being informed and causing the participant pain. For some participants, a negative experienced had a lasting effect. It caused a spectrum of feelings such as worry, helplessness, hopelessness and vulnerability. These identified barriers should not be ignored, further studies are required to understand these issues fully so appropriate strategies can be introduced to overcome them. Therefore, the current study findings not only contribute to the existing literature, but they also generates new knowledge, guiding the patient-MET relationship.

Trust is essential in the relationship between patients and healthcare professionals (Belcher & Jones, 2009; de Raeve, 2002; Rørtveit et al., 2015; Seetharamu et al., 2007). Trust has been widely discussed in the international literature and is viewed as a dynamic process evolving over time (Dinc & Gastman, 2012), while trust between patient and health care professionals is vital for decreasing patients' anxiety and allowing them to regain a sense of control (Rørtveit et al., 2015). Rørtveit et al. (2015) conducted a systematic review of qualitative studies on patients' experiences of trust in the patient-nurse relationship. From patients' perspectives, when facilitating and fostering trust the authors reported four themes: understanding the patient's need; exhibiting caring actions and attitudes; providing holistic care; and acting as the patient's advocate (Rørtveit et al., 2015). In the present study, trust and confidence, associated with the MET's competence and expertise in a demanding situation, was regularly reported by participants. In trusting the MET, participants had confidence in the decisions they made to save their lives. However, some participants did not completely trust their MET due to feeling as though they had not been thoroughly assessed, having a negative experience previously and believing their acute deterioration and subsequent MET encounter could have been avoided.

It is well documented in the literature that experiences of health care can impact a person's future health seeking behaviour and health status (Bankauskaite & Saarelma, 2003; Eriksson & Svedlund, 2007; Schwei et al., 2016). For example, a negative experience may cause a person to avoid or delay seeking further health care (Eriksson & Svedlund, 2007; Schwei et al., 2016) and distrust or suspicion of the health care system (Nickasch & Marnocha, 2009; Suurmond, Uiters et al., 2011). In a Swedish study, Eriksson and Svedlund (2007) explored hospital patients' experiences of dissatisfaction with care. The authors found that patients who were dissatisfied by the care they received during a previous healthcare experience were more likely to wait too long before consulting a healthcare professional and feel guilty for partly causing the issue themselves. In line with the above studies, the present study findings contribute to the existing body of literature that recognises patients' behaviours differ depending on their experience of health care. In particular, a delay in receiving care from the MET was perceived negatively by some participants which caused them to worry about their health as well as be concerned about further episodes of acute deterioration and MET encounters.

Studies have reported that when facing death, and when survival is uncertain, some patients find inner strength, which helps them to endure their critical illness (Alpers et al., 2012; Bergbom & Askwall, 2000; Wåhlin et al., 2009). However, when a lack of strength is experienced, patients describe feeling as though they are unable to continue or cope with their situation and a lack of will to strive for survival (Bergbom et al., 1989; Gardner et al., 2005; Gaudinski, 1977; Löf et al., 2008). In the critical review and synthesis of qualitative research on patients' experiences of critical illness, Cutler et al., (2013) reported that facing death was a major aspect for patients and had a powerful impact on their lives. For survivors, facing death contributed to a transformation in the meaning of life and what it means to be alive (Cutler et al., 2013). Another study by Alpers et al., (2012) exploring 15 critically ill patients' experiences of inner strength identified that most participants had a strong will to resist and struggle for survival although they felt scared of dying, physically weak and anxious. In line with the above studies, when facing death, participants in the current study focused their attention on their body and surviving, which included the equipment and people around them. Participants described this as energy-draining but necessary for their survival. Participants respected their MET and perceived them as valuable to their survival, no matter how they were treated.

In the literature, near-death experiences have been described as "complex experiential episodes that occur in association with death or the perception that it is impending" (Timmermann et al., 2018, p. 1). The term 'near-death experience' was originally coined by psychiatrist Dr Raymond Moody in 1975 who reported on the testimonies of 100 people who had experienced clinical death. Dr Moody suggested that survivors of near-death reported visionary experiences of heading towards a bright light through a dark tunnel. Baumann (2005) suggests that 'the light' has supernatural qualities and those who made a decision to come back from unconsciousness believed they were changed for the better. Researchers agree that near-death experiences are a complex set of phenomena but there is much debate over the basis of these experiences. Some argue a paranormal explanation over and above scientific enlightenment (Mobbs & Watt, 2011). Cant et al.,

(2012) conducted a review of the near-death experience literature to investigate the occurrence of NDEs in patients who had experienced a serious illness, injury or resuscitation event. The review identified the phenomenon of near-death experience is well established in the literature with patients experiencing a range of positive or negative cerebral effects (Cant et al., 2012). In the literature, the recurring features reported by survivors included altered sense of time, feeling of peace, seeing a bright light and feeling out of physical body. Some participants in the present study reported having experienced hallucinations and dreams during and after their MET encounter that they associated with a near-death experience. Participants described being pulled through a dark tunnel, feeling weightless and drifting away. The experience for these participants was so powerful in its impact that they questioned their mortality, the meaning of life and what it meant to be alive. Parnia (2014) provided an overview of the mental and cognitive experience of death. The author stresses that despite the nature of the occurrence, many people who have near-death experience express the need for support and greater understanding by health care professionals about their experience (Parnia, 2014). Current study findings warrant further exploration into the phenomenological and qualitative experience of near death in survivors of acute deterioration and MET encounter. The themes that have emerged from the current study provide intriguing insights into the possible cognitive experience of death and merits a genuine investigation.

Most participants in the current study expressed a sharp awareness of their own mortality having experienced a MET encounter. For many, being confronted with this reality brought on a fear of death and an awareness that death is unavoidable. Encountering a life threatening situation and the possibility of death alters a person's perception of life and reality. It can cause anxiety and tension, as well as feelings of gratitude about surviving, together with an increased concern about their acute deterioration reoccurring. In a study conducted in the UK, Inman and Ogden (2011) explored the impact of a negative event and the mechanism involved in subsequent change and adjustment. The authors interviewed 11 patients who had experienced a traumatic event such as trauma-induced stroke, liver failure, car accident, meningococcal septicaemia or a diagnosis of a life-threatening illness. Participants explained that the traumatic event made them face their own mortality which was described as 'glimpsing my mortality', 'a bloody bombshell' and 'game over' (Inman & Ogden, 2011, p. 369). The researchers suggests that "trauma is experienced in terms of an increased sense of mortality, seeing the event as an opportunity for change, the role of ongoing issues and, for many, a fear of dying" (Inman & Ogden, 2011, p. 373). Existing nursing and medical literature (Berman & Crump, 2008; Groves, 2010; Koenigsmann et al., 2006; Krigbaum, 2016; Saunders & Kimmy, 2005; Stolick, 2003) along with the current study findings, shared similar synergies around patients' realising their own mortality when experiencing a life-threatening event such as trauma, cancer and acute deterioration. Previous research suggests individuals experience a renewed appreciation of life and a positive shift in their perception of their life when experiencing an adverse event and realising their own mortality, which is conceptualised as growth (Hefferon et al., 2009; Inman & Ogden, 2011; Tedeschi & Calhoun, 2004). In light of this evidence, a study exploring the meaning of mortality and its impact in patients who experience acute deteriorator and MET encounter would contribute to the existing body of literature.

The term 'anxiety' is defined as "an emotion characterised by feelings of tension, worried thoughts and physical changes like increased blood pressure" (American Psychological Association, 2020). According to May (1977) the threat comes "from the core of one's personality, self-esteem, the experience of oneself as a person and feeling of being and self-worth" (p. 57). The threat may be to psychological existence, physical life, the threat of death, the loss of freedom and meaning, or some other value that a person identifies with (May, 1977). Death anxiety can be defined as "conscious or unconscious fear of death due to the awareness that death can occur at any time" (aan de Stegge et al., 2018, p. 59). Facing imminent death causes vulnerability as it threatens our evolutionary predestination to survive (aan de Stegge et al., 2018; Becker, 1973; Vess & Arndt, 2008). In the present study, participants experienced a spectrum of emotions such as fear, anxiety and uncertainty during and after the event. After their experience, some participants described being more aware of their physical symptoms that could cause them to deterioration and threaten their existence.

In a study conducted by Whitehead et al (2005) in the UK, the authors aimed to describe the frequency of acute distress and fear of death in patients with acute coronary syndromes. Using a mixed methods design 184 patients were interviewed an average of 2.56 +/- 1.5 days after admission. Results revealed that 73.3% of participants experienced moderate to high levels of distress and fear of dying. In another study, conducted in Germany, Albarqouni et al. (2016) aimed to describe the prevalence and factors contributing to the fear of death during myocardial infarction and its impact on prehospital delay. Using a multicentre, cross-sectional study the authors collected data over a five-year period and interviewed 592 patients. Results revealed three symptoms experienced by all participants during their acute deterioration and initial assessment: shortness of breath; sweating and chest pain. When experiencing shortness of breath, 43.2% of participants had a fear of death and 87.5% of participants had a fear of death when experiencing chest pain. The authors also suggest that patients who experience a myocardial infarction are at greater risk of depression and anxiety after the attack. This highlight the need for effective patient aftercare, where the patient's central concerns (such as fear of death) must be addressed (Albarqouni et al., 2016). Additionally, Sahan et al. (2018) conducted a study in Turkey, investigating death anxiety in

180 patients with myocardial infarction or cancer. The authors found that fear of death was higher in patients who experienced a myocardial infarction and attributed this to sudden and unexpected nature of the illness. Findings of the present study identify patients who experience acute deterioration and MET encounter suffer from acute distress and fear of death. Patients play an integral role in driving healthcare organisations to develop strategies to support patients' needs. Therefore, developing strategies to assess and manage anxiety as well as fear of death in the context of acute deteriorator and MET encounter is strongly recommended.

8.2.3 After the Encounter

The third category reflects participants' experiences, actions, feelings, and responses of their acute deterioration and MET encounter. It is of concern that survivors of acute deterioration and MET encounter may face a complicated recovery process, including fear, sadness, loss of confidence, anxiety, uncertainty, nightmares and flashbacks, hypervigilance and mistrust. The Victorian Agency for Health Information (2020) estimates that in Australia a MET or rapid response call is requested every 15.9 minutes. Jones (2014) investigated the epidemiology of adult rapid response team (RRT) patients in Australia and reported that the number of RRT calls varied considerably from 1.35-71.3/1000 hospital admissions with 10-25% of patients being admitted to a critical care area after the call. Also, one-fifth of patients who were subjected to an RRT review received more than one call during the same hospital admission (Jones, 2014). In the current study, some participants had experienced multiple episodes of acute deteriorating and MET encounters when admitted to hospital. These previous experiences formed an important role in their abilities to conceptualise their current experience.

In a literature review exploring rapid response systems by Lyons et al., (2018), the authors reported 3-9% of inpatients experienced clinical deterioration leading to a MET review. Silva et al., (2016) conducted a retrospective cohort study over a two-year period in Portugal, aiming to characterise MET activations, actions at the scene and the immediate patient outcome. The researchers reported a MET activation rate of 8.9/1000 inpatients. In a Japanese study by Kurita et al. (2016) exploring timing and location of MET activations in a tertiary hospital, the authors reported there were 336 MET activations over a period of three-years. In comparison, during 2017-2018 in Australia, 2.7% of hospitalisations involved a stay in intensive care, equating to 14.35/1000 hospital admissions (Australian Institute of Health and Welfare, 2019). Evidence suggests that survivors of critical illness experience multi-dimensional compromise during their recoveries and after ICU admission (Aitken & Marshall, 2015; Turnbull, 2016). In recent years considerable efforts have been made to develop, refine and improve interventions to promote recovery from critical illness (Aitken & Marshall, 2015). To date, there are no published studies exploring or evaluating strategies to support patients who have experienced acute deterioration and MET encounter. This is concerning as potentially only 10-25% of MET survivors will receive recovery support because they are admitted to a critical care area.

There is extensive evidence that survivors of critical illness experience multifaceted compromise during their recoveries (Aitken & Marshall, 2015; Needham et al., 2012). The recovery trajectory can often extend for weeks to years and is different for each patient (Aitken & Marshall, 2015). In the current study, during the recovery phase participants encountered ongoing challenges such as uncertainty and loss of confidence in their physical condition, especially the ability to cope with symptoms of a chronic condition. From the study findings, it suggests the recovery trajectory may be impacted by patient’s pre-existing health issues and their psychological status, therefore being unique for each individual. For example, the proportion of intensive care unit (ICU) patients surviving until hospital discharge have risen steadily over recent decades (Carson et al., 2012; Needham et al., 2005; Zilberberg et al., 2012; Zimmerman et al., 2013). As a result of these trends, the number of ICU survivors is growing (Turnbull et al., 2016). However, critical illness survivorship often comes at a cost, with many survivors experiencing new and long-lasting physical (Fan et al., 2013; Fontela et al., 2018; Herridge et al., 2011), cognitive (Pandharipande et al., 2013), and mental health sequelae (Davydow et al., 2008; Davydow et al., 2009; Parker et al., 2015) as well as impaired quality of life (Dowdy et al., 2005; Dowdy et al., 2006). Due to the increasing number of ICU survivors, professional organisations, such as Multi-society Task Force for Critical Care Research, have suggested prioritising research on the outcomes of survivors of critical illness after hospital discharge (Carson et al., 2012; Deutschman & Tracey., 2014; Needham et al., 2012; Spragg et al., 2010; Turnbull et al, 2016).

It is not difficult to imagine the sense of fear, uncertainty and helplessness participants in the current study experienced when in severe pain, unable to breathe or communicate and disorientated to time. For some patients, this stress-reaction may become traumatic, impacting on a range of psychobiological processes (Corrigan et al., 2007). Consequently, patients may develop acute stress disorder and posttraumatic stress disorder (American Psychiatric Association, 1994). According to the Australian guidelines for the prevention and treatment of acute stress disorder (2020), posttraumatic stress disorder and complex posttraumatic stress disorder, exposure to a potentially traumatic event can be direct and experienced on a single occasion, or repeatedly (Phoenix Australia, 2020). In the early aftermath of a traumatic exposure, it is common and considered normal, for a person to experience some degree of psychological distress such as upset, increased anxiety, sleep and appetite disturbances, fear, sadness, guilt or anger (Phoenix Australia, 2020). But, if these symptoms last longer than two days following the event, a diagnosis of acute stress disorder may be considered (Phoenix Australia, 2020). If these symptoms persist beyond a month, a diagnosis of posttraumatic stress disorder may be considered (Phoenix Australia, 2020). Most of the participants in the current study were interviewed more than two days after their acute deterioration and MET encounter with many continuing to experience anxiety, loss of confidence, fear, hypervigilance and uncertainty. This study suggests that patients who experience acute deterioration and MET encounter are at risk of acute stress disorder and posttraumatic stress disorder.

Acute stress disorder is considered a risk factor for the development of posttraumatic stress disorder which is associated with impairments in social function, quality of life and cardiovascular health (Bryant, 2011; Ginzburg & Ein-Dor, 2011; Meister et al., 2015). Acute stress disorder is the most significant stress reaction diagnosis within the first month after exposure to a traumatic event (Ginzburg & Ein-Dor, 2011). In the literature, illnesses such as cancer (Kangas et al., 2007), spontaneous abortion (Bowles et al., 2006), myocardial infarction (Ginzburg et al., 2003) and burns (McKibben et al., 2008; McLean et al., 2017; Resenburg et al., 2015) have been associated with the prevalence of acute stress disorder. In patients with acute coronary syndrome, such as myocardial infarction, the prevalence of acute stress disorder was found to be 18% when assessed with a clinical questionnaire (Ginzburg et al., 2003). In an American study by McKibben et al. (2008) the authors investigated the utility of self-report measures in detecting acute stress disorder and posttraumatic stress disorder in patients with major burn injuries, and in the tracking and predicting posttraumatic stress disorder. The researchers used the Stanford Acute Stress Reaction Questionnaire to assess acute stress disorder symptomatology at discharge and the Davidson Trauma Scale to assess posttraumatic stress disorder symptoms at one month, six months, 12 months and 24 months. Of the 178 participants, the authors reported the prevalence of in-hospital acute stress disorder to be 23.6% with 35.1% for posttraumatic stress disorder at one month and 42.7% from one month to 24 months (McKibben et al., 2008). There are currently no published studies exploring acute stress disorder and posttraumatic stress disorder in patients who have experienced acute deterioration and MET encounter. The identified psychological distress of fear, uncertainty and helplessness experienced by participants in the current study should not be ignored, further studies are required to understand this fully, so appropriate strategies can be introduced to overcome them.

Commonly, post-traumatic stress syndrome occurs amongst critical care survivors, impacting approximately one in ten patients who have an admission greater than 48 hours (Teece & Baker, 2017). Hashem et al. (2016) conducted a systematic review of qualitative studies evaluating patient outcomes for survivors of critical illness. The authors identified posttraumatic stress disorder symptoms as a common theme throughout the literature. The symptoms included recurrent dreams/nightmares or flashbacks related to the illness and intensive care admission, negative emotions when reminded of the critical illness, anxiety, constant fear, worrying, panic attacks and feeling "on guard". Consistent with these findings Talisayon et al., (2011) investigated the prevalence and severity of posttraumatic stress disorder symptoms in critically ill patients who had been mechanically ventilated in Australia. Study participants (n=97) completed the Impact of Event Scale within one week of hospital discharge. The results revealed survivors experienced distorted perception and gaps in memory, fear of recurrence of illness, avoidance, sleeping problems and distress. Considering the current study findings, we can hypothesise that survivors of acute deterioration and MET encounter may experience acute psychological stress contributing to acute stress disorder and potentially posttraumatic stress disorder. In order to develop strategies to alleviate psychological consequences, it is vital to characterise acute deterioration psychological distress and begin to understand its causative and protective factors.

Some current study participants discussed wanting to talk about their experiences as it could help them understand what occurred and address unanswered questions. In particular, one participant suggested that after the event patients should be provided with a debriefing session like healthcare professionals receive. Clinical debriefing is well established in healthcare, it is a powerful reflective tool for clinicians to enhance their learning and deliver safe patient care (Schmutz & Eppich, 2017). Commonly, clinical debriefing is used as a learning tool following a simulated event and a mandatory activity for staff who have experienced a traumatic occurrence such as code blue, MET or patient violence. For healthcare professionals, studies suggest clinical debriefing can relieve stress, increase motivation, confidence and self-esteem as well as improving job security and satisfaction (Coggins et al., 2020; Nadir et al., 2017; Song & Baicker, 2019). Although, if not targeted appropriately it has been suggested debriefing could cause possible harm (psychological trauma, social relations and learning trajectories) (Carlier et al., 1998; Coggins et al., 2020; Kagee, 2002; Vaithilingam et al., 2008). In contrast, recent studies suggest the benefits of clinical debriefing (enhanced learning, team performance and patient outcomes) outweigh potential risks (Couper et al., 2013; Farrington et al., 2019; Rose & Cheng., 2018; Wolfe et al., 2014). In light of challenges faced by present study participants, there is a need to establish effective interventions, such as clinical debriefing, to support patients who experience acute deterioration and MET encounter.

Psychological debriefing and critical incident stress debriefing are described in the literature as immediate interventions to relieve stress and prevent long term distress for survivors of trauma (Devilly & Cotton, 2003). According to Davis (2013), critical incident stress debriefing is a technique designed to assist a person dealing with the physical or psychological symptoms that are generally associated with a traumatic event and can occur at the bedside. After an extensive literature search, no studies were found exploring clinical debriefing, psychological debriefing, critical incident stress debriefing or debriefing from the perspective of the patient or evaluated outcomes. What was found was one news in brief article stating patients were grateful for telephone debriefing after discharge from intensive care ("The Lamp," 2005). The literature found explored tips for facilitating and implementing clinical debriefing programmes (Coggins et al., 2020; Clapper, 2016); debriefing from the perspective of students (Bernard et al., 2017; Kang & Mi, 2018; Kitson-Reynolds, 2015; Lavoie et al., 2017; Nagle & Foli, 2020; Reed, 2013; Timmis & Speirs, 2015) and healthcare professionals (Dougan et al., 2019; Keene et al., 2010; Leff et al., 2017; Park & Holtschneider, 2016; Rose & Cheng, 2018; Vaithilingam et al., 2008). Our findings suggest the needs of patients who have experienced acute deterioration and MET encounter are multifaceted, complex and not routinely assessed or addressed throughout their illness-recovery trajectory. The view of acute deterioration and MET encounter through the lens of survivors gives unique and powerful insights into the challenges patients face but also the supports they would value during this time. By identifying and understanding patients' emotional, physical and cognitive experiences it is an important step towards determining what supports they need.

Globally, healthcare standards have been developed to protect the public from harm and improve quality of health service provision (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2017; Chung et al., 2020; NICE, 2018). Recognising and responding to acute deterioration is a priority standard that aims to ensure acute deterioration is recognised promptly and appropriate action is taken (ACSQHC, 2017). However, the guidelines do not provide clinicians with strategies to support patients during and after the MET encounter. Present study findings suggest participants move through a process of acceptance such as dealing with a potentially life-threatening illness, emotions such as fear and uncertainty, accepting what the MET needs to do, and self-evaluation. A search of the literature revealed no clinical guidelines nor recommendations available to improve the quality of care received by patients during and after a MET encounter. Therefore, based on the current study findings, it is recommended that guidelines, protocols and care pathways be developed to ensure health care professionals deliver consistent and efficient care to patients who have experienced acute deterioration and MET encounter with the aim of improving their recovery and minimising potential harms.

As stated previously, approximately 10-25% of patients who experience acute deterioration and MET encounter will be admitted to intensive or critical care units after the event (Jones, 2014). It is well established in the critical care literature that intensive care patients need care that extends beyond their critical illness to enable them to reclaim their lives post discharge (Kean et al., 2016).

The impact of critical illness is now being referred to as post intensive care syndrome and has gained extensive international research attention, often by using standardised measure of psychological outcome or quality of life (Cuthbertson et al., 2010; Davydow et al., 2008; Parry et al., 2017; Schandl et al., 2011). Post intensive care syndrome describes the cognitive, psychological and physical impairments that remain with survivors of critical illness admitted to intensive care that negatively affect their quality of life (Rawal et al., 2017). Due to the increased post intensive care syndrome-related research, interventions are being introduced to prevent or reduce post intensive care syndrome such as ICU diaries, early rehabilitation, counselling and home rehabilitation (Castro-Avila et al., 2015; Engstrom et al., 2009; Garrouste-Orgeas et al., 2012; Jensen et al., 2015; Sosnowski et al., 2018). In contrast, the social and economic impacts of acute deterioration and MET encounter are under-researched and we have little understanding of how different dimensions of acute deterioration and MET encounter interact to produce far reaching changes to survivors' lives (Guinane et al., 2018). This is a serious oversight if we are to ensure appropriate services are developed to support this patient group. Therefore, the theory derived in this study, *Unravelling a complex experience: Conceptualising a patients' experiences of acute deterioration and MET encounter,* could be utilised as a framework for intervention development and future measurement tools.

The emerging picture of acute deterioration and MET encounter survivorship is unsettling with its impact being relatively unknown. On reflection, being seen as a person rather than objectified as a physical body or disease, had significant meaning for participants in this study. Participants suggested better communication from the MET and being part of decision-making processes was important because it meant they were being treated holistically. When participants were satisfied with communication and felt they were involved in their own care, they perceived they were in good hands with the MET. When participants thought communication and their involvement was lacking, they felt powerless and their illness became their defining features. Patient-centred care, also known as person-centred care, is a broad concept, covering a wide range of different strategies and approaches. Despite no globally accepted definition, the proposed definitions encompass similar core concepts based on research conducted by the Picker Institute and Harvard School of Medicine in 1993. In a report titled *Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care,* the authors identified the dimensions of respect for patients' preferences and values; emotional support; physical comfort; information, communication and education; continuity and transition; coordination of care; the involvement of family and friends; and access to care (Gerteis et al., 1993). These principles and approaches are means of potentially achieving better health outcomes and supporting greater involvement of all people in the healthcare process. The World Health Organisation (WHO) uses the term ‘responsiveness’ instead of patient-centred care which describes how a healthcare system meets people’s expectations, respects their wishes and ensures effective communication between healthcare professionals and patients (WHO, 2000). Several studies have identified and explored concepts of patient-centred care (Cronin, 2004; Goodrich & Cornwell, 2008; Robb & Seddon, 2006) and according to the International Alliance of Patients’ Organisations, “the most common element in definitions of patient-centred care is respect for the needs, wants, preferences and values of patients” (Groves, 2010, para. 8). Results of the current study suggest patients who experience acute deterioration and MET encounter may not receive patient-centred care that is respectful of, and responsive to their individual preferences, needs and values (ACQSHC, 2017). Therefore, when caring for an acutely deteriorating patients during a MET encounter, health care professionals need to shift their thinking into empowering patients to take an active role in their care.

Patient-centred care has been identified as an essential foundation for health-care quality and patient safety but despite many efforts to practise patient-centred care, most health-care systems are challenged by effective implementation across the continuum of care (Institute of Medicine, 2001; Santana et al., 2017). The MET encounter can be a high-pressured, high-stress, high-challenged environment where patients’ lives can be positively and negatively impacted. Findings from this current study suggest local features such as building a relationship with the MET, communication, developing of personas, emotions, acceptance and facing death may both support and hinder aspects of patient-centred care. For example, patients experiencing acute deterioration and MET encounter may not be able to be involved in the decision making process and treatment plan when they are experiencing severe pain, shortness of breath, dizziness and are unable to communicate. Commonly, patient acuity demands a focus on measurements, technology support, monitoring and titration of interventions and medications to regulate physiological bodily function (Jakimowicz et al., 2017). Conceptually, patient-centred care is a model that aims to ensure individuals receive high-quality care and improve health-care system efficiency and effectiveness by encouraging health-care providers and patients to co-design personalised care (Santana et al., 2017). Although many conceptual frameworks of patient-centred care have been presented and discussed in the existing literature (Constand et al., 2014; Ekman et al., 2011; Guinane et al., 2018; Kison et al., 2012; Lusk & Fater, 2013; McCormack & McCance, 2006; Pelzang, 2010; Scholl et al., 2014), guidance on how to implement patient-centred care has not been well described, especially in the acute deterioration literature.

In an Australian study, Glasson et al. (2006) used a mixed methods triangulated study to improve the quality of nursing care for older acutely ill hospitalised medical patients through developing, implementing and evaluating a new model of care. The authors modified The Barthel activity of daily living Index (Mahoney & Barthel, 1965) to incorporate Orem's self-care requisites (Orem, 2001). Findings suggest positive clinical outcomes such as greater knowledge about their treatment and management plan, improved activities of daily living and earlier discharge. Whereas Hardin and Kaplow (2017) suggests the Synergy Model (a conceptual framework where patients' needs drive the nursing competencies required for patient care) is the most suitable framework in the critical care setting as it transforms a technical, potentially impersonal setting into a humane and healing place (Hardin & Kaplow, 2017). There is evidence that the concepts inherent of patient-centred care have positive outcomes for critically ill patients. In a discussion paper, Feo and Kitson (2016) explored patient-centred fundamental care and why it is overlooked in sophisticated, high technology acute care settings. The authors argue that the dominance of the biomedical model as well as managerial approaches cause the fundamental principles of patient-centred care to be overlooked and devalued (Feo & Kitson, 2016). While patient-centred care is not a new concept, an increasing emphasis has occurred over recent years as it has become the cornerstone of quality healthcare and is explicitly referenced in healthcare policy (Delaney, 2018; SA Health, 2015). Developing an integrated model of patient-centred care focused on the needs and priorities of patients who experience acute deteriorating and MET encounter would be invaluable. Therefore, the emergent theory and framework has important implications for both practice and policy.

8.3 Study Recommendations

With the growing impetus for gathering patient experience data, our constructed theory is timely as it provides insights and a framework for patients' experiences and the challenges they encounter when experiencing acute deterioration and MET encounter. This theory offers opportunity to identify ways in which these challenges could be addressed, and strategies planned to overcome them. Recommendations arising from the study for clinical practice, research and education are discussed next.

8.3.1 Recommendations for Clinical Practice

Patient experience data is recognised globally as a means of assessing healthcare delivery with many countries now gathering patient experience or satisfaction data (Chung et al., 2020; Edwards et al., 2014). For example, in the UK, the National Institute for Health and Care Excellence (NICE) developed quality standards to prioritise areas for quality improvement in health and social care (NICE, 2018). One of those quality standards is *Patient experience in adult National Health Services (NHS)* which aims to ensure patients receive compassionate care and are treated with dignity, respect, understanding and honesty (NICE, 2018). In Australia, the National Safety and Quality Health Service (NSQHS) standards aim to improve quality of health service provision and protect the public from harm (ACQSHC, 2017). *Standard 2 – Partnering with Consumers Standard* recognises that consumer partnerships in health care are integral to the development, implementation and evaluation of health policies, programs and services (Consumer Health Forum of Australia, 2015; Dalton et al., 2015; Johnson., 2015). In Western societies, patient experience data is recognised as a crucial indicator of quality in healthcare provision and is commonly cited in national and international health policy (National Health Service, 2013).

The proposed model has the potential to inform health policy to guide consumer reporting of patient deterioration required by national safety and quality health-care service standard in across the world. Our theory recommends that healthcare organisations gather data about patients' experiences of acute deterioration and MET encounters for quality assurance. This could be achieved in the form of patient feedback survey, designed to allow patients to provide anonymous feedback about their experience. Also, it is recommended that a MET rating tool be developed that contains core items that can form part of standardisation at the national level to allow comparisons of patients experience across a number of health care settings. The results of the feedback back survey and MET rating tool could be used to identify training needs to ensure healthcare professionals who form the MET are well equipped to care for the acutely deteriorating patient during and after a MET encounter. The identified training needs could inform annual basic life support (BLS) and advanced life support (ALS) training and assessment.

Study results create a call for healthcare services to instigate strategies to support patients who have experienced acute deterioration and MET encounter. In order to support patients, the introduction of debriefing and patient follow-up by appropriately trained staff is crucial. Providing sufficient resources and adequate supports such as this reflects a vision and priority by health care organisations to ensure patient centred care as well as meeting safety and quality healthcare standards implemented around the world. In addition, accessibility to appropriately trained staff to provide after care is an essential strategy to ensure patients wellbeing.

The findings of this study suggest the patient-MET relationship is a central influence on a patient’s experience. Therefore, with the aid of professional supervision, member of METs are encouraged to undertake clinical debriefing and reflection after each MET encounter. Reflective practice will enhance self-awareness regarding how health professionals deliver patient care. All healthcare professionals need to receive reflective practice training which could be included in annual basic life support and advanced life support training programs.

Finally, results from this study reveal that globally, there are no clinical guidelines, protocols or care pathways available to guide health care professionals to care for patients throughout the illness-recovery trajectory of acute deterioration and MET encounter. Participants in this study have revealed concerning aspects about their experience such as fear, uncertainty, facing death, loss of time and memory, feeling like a number, confusion about what occurred and why, difficulty in accepting events and some lasting psychological and physical impacts. Therefore, it is crucial that a panel consisting of all relevant groups be convened to develop clinical guidelines to improve the quality of care and health outcomes for patients who experience acute deterioration and MET encounter.

8.3.2 Recommendations for Future Research

At the commencement of this study, little was known about the experience of acute deterioration and MET encounter from the perspective of the patient. It is expected that the findings of the study and consequential recommendations will stimulate future research exploring topics including:

1. Exploring patients’ experiences of acute deterioration and MET encounter plays an important role in preparing healthcare professionals to provide holistic care. Yet, how patient experience data can impact patient care, care delivery and patient outcomes

presents an area for essential research. Therefore, further research is required to investigate how patients' experiences of acute deterioration and MET encounter can improve practice, patient outcomes and service delivery is strongly recommended. A patient-reported outcome measures (PROM) tool must be developed to assist healthcare organisations improve patient care.

2. There is a paucity of literature exploring patients' experiences and needs after acute deterioration and MET encounter. The study findings suggest patients have a lasting impact which must be addressed. A longitudinal study exploring patients' perceptions, experiences and needs over time after experiencing acute deuteriation and EMT encounter is strongly recommended. This would allow healthcare organisations to develop resources to assist healthcare providers to identify patients who may have on-going issues to improve patient care and outcomes.
3. Examining ways in which data on patient safety, patient experience and clinical outcomes interconnect would provide useful insights to develop strategies to support patients experiencing acute deterioration and MET encounter. Also, examining outcomes of these strategies will guide healthcare services to plan strategically.
4. The study findings suggest patients' perceive their experience as negative when the MET fails to build a therapeutic relationship with them, specifically poor communication impacts trust, safety, and confidence. Therefore, further research into identifying strategies to enhance health care professionals communication skills to improve collaboration with patients during a MET review is strongly advised.
5. Many participants were left with unanswered questions such as why their acute deterioration occurred and what happened during their MET encounter. Future research could explore how patients are delivered and receive information about their conditions and management. An understanding of what constitutes effective communication during a critical event requires further investigation.
6. From the study findings, patient debriefing is highly recommended; however, its practical implementation and influence on patients' outcomes is mostly unknown. Therefore, future research exploring the implementation of patient debriefing and its impact would be highly valuable.
7. This study presented the perspectives of the patient only. Therefore, exploring the perspectives of healthcare professionals, the MET and family members present during the event could aid in further understanding the phenomenon.

8. Gathering patient experience data is essential for health-care quality and patient safety. Many current patient experience tools are not designed to address the unique care aspects of a MET encounter. Therefore, the development of a MET rating tool would allow patients to provide health organisations with feedback to ensure care quality.
9. The constructed theory and study findings present an Australian context only, hence further studies are needed to test the theory in the global context.
10. The application of the theoretical framework developed from this research should be explored in relation to patients' experiences of other clinical events, or other groups of patients excluded from the current study, such as obstetric or paediatric.

8.3.3 Recommendations for Education

There are several areas of education that can incorporate the findings of the research, with the aim of creating more awareness and understanding of patients' experiences of acute deterioration and MET encounter. This research demonstrates that healthcare professionals may not be well equipped to meet the needs of acutely deteriorating patients experiencing a MET encounter. At a tertiary level, the findings could be integrated into health professional curricula (undergraduate and postgraduate) to create awareness and understanding of what it is like to experience acute deterioration and MET encounter. This could be in the form of simulation case-based scenarios within practice-based courses, using guest speakers who have survived acute deterioration and MET encounter and as part of simulation-based education programs. Undergraduate and postgraduate health care professionals would be better situated to provide care that is informed by research, thus providing evidence-based practice.

Patient's experiences of acute deterioration and MET encounter offers a unique insight into healthcare quality and patient safety. These experiences can be used to facilitate healthcare professionals, especially MET members, reflective learning. Reflective learning is defined as 'an experiential process of personal insight development, in which one's own and others' experiences produce change in behaviours' (Brookes et al., 2019). In this study, patients described what they thought as 'good' and 'bad' MET. Each provide important opportunities for learning and improvements through reflection. In the literature, reflective learning has been described as a way of improving personal insight development and behaviour change leading to improved health care delivery, attitudes and behaviours of healthcare professionals and staff-patient relationships (Brookes et al., 2019). Therefore, study findings could be used to develop reflective learning opportunities, specifically for MET's, such as workplace-based activities and internet-based resources to improve healthcare professionals understanding of what it is like for patients to experience acute deterioration and being cared for by a MET.

8.4 Study Limitations

Documenting limitations to research can be beneficial when reflecting on the process and identifying elements that could be improved, included or omitted in future research opportunities. Traditionally, limitations centre on the number of participants, and whether findings can be generalised to a broader populations. However, such limitations are not congruent with the methodology of grounded theory applied in this thesis. Research findings conducted within the interpretive domain are not meant for generalisation to the broader environment as is typical of qualitative research (Bryant & Charmaz, 2010; Ralph, 2013). The substantive theory of *Unravelling a complex experience: conceptualising patients' experiences of acute deterioration and MET encounter* is limited to the context in which the study took place – three healthcare services in regional Victoria, Australia. The constructed theory as an outcome of the study can be verified but is not necessarily replicable. However, the emergent theory offers a valuable framework for explaining similar phenomena which can be used to explore patients' experiences in other clinical areas.

Another limitation of this study is related to participants, as participation in this study was voluntary and may not reflect all perspectives. There may have been potential participants who were traumatised by their MET encounter who did not want to discuss their experiences with a researcher. Although, in this study only two participants who were approached declined to participate. It is also assumed that all participants were truthful in their responses when sharing their experiences. The current study was limited as the researcher explored this phenomenon only from the patient's perspective. However, a strength of this study was the recruitment of participants across difference health services from a range of clinical settings, therefore the theory provides a valuable reference for patients across clinical areas. There were 10 male and 17 female participants with a majority aged above 50 years and born in Australia. Some may question the credibility of the study due to the similar background and ages of the participants, suggesting a skewed participant group. However, the cohort of participants in this study were reflective of the population from which they could be drawn. Furthermore, it is unlikely that younger patients would experience acute deterioration and MET encounter.

Finally, although the process of data collection including conducting interviews, writing field notes and memoing provided rich sources of data, there were time constraints between interviews. If multiple interviews occurred on the same day and a recorded interview could not be transcribed and analysed before the next interview, the researcher listened to the audio-recording, made notes and changed the interview guide as required.

8.5 Summary of Chapter Eight

In this chapter, the substantive theory and categories considering the global literature were presented. Implications and recommendations for research, practice and education have also been discussed. Study limitations were addressed which provided insights into the challenges from a methodological perspective. Patients play an important role in driving healthcare organisations' strategies to adopt screening policies and practical management for patients who experience acute deterioration and MET encounter. Although the use of patient experience data in the development of guidelines is a relatively new notion, methodologically and conceptually, it requires significant improvement in the future. In the next chapter, the thesis is concluded by presenting a summary of the study findings, as well as a discussion of the evaluation criteria used to establish trustworthiness and rigour of the constructed theory.

CHAPTER NINE

Conclusion

Chapter Nine: Conclusion

9.1 Introduction

The following research question, introduced in Chapter One, was explored using a CGT approach.

> What processes occur as patients experience acute clinical deterioration and MET encounter?

In this closing chapter, a brief summary of the findings and criteria used to evaluate the constructed theory is provided.

9.2 The Study

This thesis reports on a study of acute deterioration and MET encounter from the perspective of the patient. The objective of the study was to generate a substantive theory about the processes patients engage in when experiencing acute clinical deterioration and MET encounter. A scoping review conducted in the initial stages of the study in 2018 indicated that patients experience perceptual, emotional and physical distress during acute deterioration. The review highlighted there were no studies exploring patients' experiences of acute deterioration and the initial medical emergency management they receive. Therefore, it confirmed the need for the study to explore and develop an in-depth understanding of patients' experiences of acute deterioration and MET encounter. GT underpinned by symbolic interactionism was chosen as the most suitable methodology to address the aim of this research. CGT informed by Kathy Charmaz (2006, 2014) was used to develop a theoretical understanding of patients' experiences of acute deterioration and MET encounter. Data was collected from three Australian healthcare services, between May 2018-May 2019. One-to-one interviews were undertaken resulting in 27 individual interviews. The data was transcribed verbatim and analysed concurrently using constant comparative method.

The findings of this study describe patients' actions, processes and interplays with the clinical environment when experiencing acute deterioration and MET encounter through the theoretical model entitled '*Unravelling a complex experience: Contextualising patients' experiences of acute deterioration and MET encounter*.' Many participants began their journey by experiencing physical symptoms that made them recognise their own acute deterioration. For many, this realisation caused them to experience emotional changes such as fear and anxiety. For all participants, experiencing physical and emotional changes resulted in a MET encounter. During the MET, the recollections of participants varied from no, limited or vivid recall of events. For those who had limited to no recall of their MET encounter, what they did recall was of significance to them.

Participants described the relationship they had with members of the MET as a central influence on their experiences. Participants relayed that their level of satisfaction, comfort and coping was dependent upon the relationships formed with members of their MET. Participants often adopted different personas while being cared for during their MET encounter. Two main personas emerged: recipient and consumer. The consumer persona typically was chosen by the participant whereas the recipient persona was assigned to the participant by the MET. Many participants perceived they were in good hands with their MET, having trust and confidence in the MET's ability to care for them and save their lives. Some participants were uncertain as to whether they would live or die, they focused their attention on surviving which included any equipment or person that could help them. After the MET encounter, participants need for knowledge and understanding about their illness was of great importance for their self-care and recovery. Some participants searched for deeper understandings about their illness and the events that occurred, whereas other were less reflective and felt they could manage without further understanding. From the data, contextual factors emerged that influenced participants' experiences. Some participants identified that their acute deterioration and subsequent MET encounter was unexpected, and they perceived the nature of their illness as stable based on what they had been told by medical staff. Many acknowledged that their experience was dependent on the health care professionals who were caring for them at the time. Past experiences of illness and hospitalisation played an important role in participants' abilities to conceptualise their experiences of acute deterioration and MET encounter.

It is paramount that healthcare organisations gather data about patients' experiences of acute deterioration and MET encounters to instigate strategies to support patients. *"Unravelling a complex experience: Conceptualising patients' experiences of acute deterioration and MET encounter"* is a unique theoretical model that offers understanding of participants' actions, processes and behaviour, as a response to the central problem. The theory is considered substantive in nature as it is constructed from exploring a phenomenon in a specific context, hospital inpatients who experienced acute deterioration and MET encounter. Considering the study findings, a series of recommendations (chapter eight) have been made and the constructed theory generates new knowledge in the nursing literature, particularly in the context of patients' experiences of acute deterioration.

9.3 Evaluating the Grounded Theory

According to Elliott and Lazenbatt (2005), a grounded theory study is not evaluated exclusively by qualitative criteria (*credibility, dependability, transferability and confirmability*), instead by the constructs that were used to develop it. To evaluate the quality of a GT study, Strauss and Corbin (1990) suggest 10 basic and 13 additional criteria, whereas Glaser (1992) evaluates the quality of a GT study by *fit, work, relevance*, *modifiable, parsimony* and *scope*. However, Charmaz (2014) takes the evaluation further and engages the criteria of *credibility* (logical and conceptual grounding), *originality* (significance of the study), *resonance* (offers meaning and scope for all those for whom it may be relevant) and *usefulness* (knowledge development and practical application), evaluation criteria supported by Corbin and Strauss (2008). In this study, the contemporary approach by Charmaz (2014) was used as it is both comprehensive and logical. Charmaz (2014) places emphasis on the application of evaluative criteria in accordance with the purpose and context of the study (Birks & Mills, 2015). According to Berthelsen, Grimshaw-Aagaard and Hansen (2018), researchers must be specific about the chosen approach and they must present and explain its criteria for evaluating the quality of a GT study, in order to allow the reader to assess the consistency of the GT study.

9.3.1 Credibility

Credibility refers to how much the data collection accurately reflects the multiple realities of the phenomenon (Sikolia et al., 2013). Credibility is also judged by the documented methodological steps taken by the researcher, in the form of audit trails, memoing and peer debriefing (Bowen, 2009; Foley & Timonen, 2015). Charmaz (2006) suggests that credibility is achieved when the researcher attains intimate familiarity with the topic and provides sufficient depth of data to merit their claims.

In this study, credibility was achieved in several ways. Theoretical sensitivity was developed from reading the relevant literature and the researcher’s personal experience as a practising acute care nurse. The researcher was also immersed in participants’ worlds over a 12-month period which enabled familiarity and enhanced understanding of the phenomenon. When presenting the study findings, participants’ words were embedded throughout which demonstrates strong links made between data and analysis. A constructivist approach to grounded theory understands that both data and analysis is created from shared experiences and relationships with participants (Charmaz, 2014). Therefore, efforts were made throughout the study process to ensure the researcher’s preconceived assumptions and biases were not imposed on the study findings. Asides from being immersed in the data, the researcher used strategies, such as maintaining a methodological journal and memo writing. A methodological journal allows the researcher to engage in reflexivity to avoid preconceiving the data (Charmaz, 2014), whereas memo writing facilitates reflection and understanding of the phenomenon in the form of theoretical notes (da Silva et al., 2018).

Credibility was also achieved by collecting data from a wide range of participants and events. This depth and breadth of data ensures a broad range of behaviours are explored in different settings, giving merit to the theory (Hall, 2013). Using one-on-one interviews, patients were recruited from a variety of clinical settings across three different health services gaining valuable insight into the phenomenon from different perspectives. Corbin and Strauss (2008) suggest that analysing data collected from a wide range of participants and events ensures each category is fully developed and assists the researcher to check their interpretations against alternative explanations. In this study, the properties and dimensions of all categories were explored in a variety of contexts to ensure the theory was reflective of the experience of all participants. Furthermore, although GT methods make member checking redundant as a source of verification (Charmaz, 2014; Birks & Mills, 2015), some interviews were subjected to member checking to confirm that interpretations aligned with participants' meanings and experiences

Credibility was also achieved by using essential methods of constant comparative analysis and theoretical sampling. The continuous and simultaneous collection, coding and analysing of the data throughout the research process allowed the researcher to make analytic sense of the data, to challenge, check and test initial ideas. Categories were constantly compared with codes and data, ensuring they were correctly interpreted participants' experiences and meanings they assigned to them. This process ensured strong links were made between categories and interpretations were discussed with study supervisors. In addition, an audit trail was maintained by keeping accurate records on theoretical and methodological decisions regarding developed categories and the constructed theory. This will allow future researchers to follow or replicate the process.

9.3.2 Originality

When considering the originality of the study, Charmaz (2014 p. 337) asks the questions: "*Are the categories fresh? Do they offer new insights? Does your analysis provide a new conceptual rendering of the data? What is the social and theoretical significance of this work? How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?*"

Over the last decade, the body of knowledge in the recognition and management of acute deterioration has increased considerably but patients' experiences have received little attention from researchers. The only similar work conducted previously in Australia was by Guinane et al.

(2018) who explored the experiences of patients who received a MET review with a focus on Patient and Family Activated Escalation System. The current study allowed a broader perspective of patients' experiences of acute clinical deterioration and being cared for during a MET review. This research was strengthened by the recruitment of participants from a range of healthcare settings and not confining the study to one hospital, this allowed the researcher to explore many viewpoints.

The theoretical model offers a possible explanation of how patients respond to their own clinical instability. The theory extends the current understanding of the phenomenon and contribute to the new knowledge in the paradigm of acute deterioration. The theory cannot be generalised, but it provides a framework for explaining processes common to the phenomenon and can improve patient care by raising awareness of patients' experiences. This theory highlights key issues for practice and has the potential to inform health policy to guide consumer reporting of patient deterioration required by national safety and quality health-care service standard in across the world. The study and theory meets the criteria of originality and significantly contributes to the existing body of knowledge.

9.3.3 Resonance

Charmaz (2006, 2014) refers to resonance as the ability of the findings to portray fullness of the studied phenomenon and make links to the broader context. To ensure resonance in this study, data were continually collected and analysed until theoretical saturation was achieved. Care was taken to ensure that the developed theory resonates with participants' experiences, and the meaning they assigned to the processes they undertook. This was ensured by staying close to the words of participants by continuously referring to the transcripts and listening to audio-recordings. Charmaz (2006, 2014) highlights that the grounded theory should make sense to the participants and offer a deeper insight about their worlds. In this research, once categories were fully saturated and the theory was constructed, two participants were contacted to see if the interpretation of the theory reflected their experiences. The participants commented:

> *That is exactly what happened, you have described my experience very well. To be honest, I still don't fully understand what happened to me and it was over two years ago (Kelly).*
>
> *Yes, this is very accurate to what my experience was like. It happened so quickly and was over almost as fast. It's interested to unpack it like you have, overall, it really is a complicated experience (David).*

Returning to participants with abstract theory helps the researcher determine if the theory is grounded in the data (Malik, 2017). It also helps to identify if further data collection or in-depth analysis is required to strengthen the theory (Malik, 2017). According to Charmaz (2014), a "strong combination of originality and credibility increases resonance, usefulness and the subsequent value of the contribution" (p.338). While the above comments offer new insights it also meets the criteria of credibility, originality and resonance. For example, one participant said that after two years she had a clear recall of the encounter but still did not understand what occurred and why.

9.3.4 Usefulness

Charmaz (2014, pg. 338) suggests usefulness is evaluated by asking such questions as: "*Does your analysis offer interpretations that people can use in their everyday world? Can the analysis spark further research in other substantive areas? How does your work contribute to knowledge? How does it contribute to making a better world?"* Therefore, the constructed theory '*Unravelling a complex experience: Conceptualising patients' experiences of acute deterioration and MET encounter'* should be practical and contribute to the body of knowledge. In accordance with this evaluation criteria, the findings have highlighted several practice, research and education recommendations, as discussed in Chapter Eight and presented at participating health services. The constructed theory does not only contribute to the body of knowledge, but it also provides vital insights into patients' experiences which offers a means of enhancing patient care. Not only has the theory highlighted many challenges within each category, but it also generates idea for future research.

9.4 Concluding Remarks

This final chapter brings the thesis to a close by providing a synopsis of the study and outlined the study aims. The purpose of this study was to explore processes that patients undertake when experiencing acute deterioration and MET encounter. In doing so, a substantive theory, *Unravelling a complex experience: endeavouring to contextualise patients' experiences of acute deterioration and MET encounter,* emerged. The emergent theory leads to recommendations that healthcare organisations gather data about patients' experiences of acute deterioration and MET encounters, as these are valuable, relevant, meaningful and emotionally salient. Findings provide an explanatory framework for similar phenomena and increase awareness of patients' experiences to ultimately inform health policy and improve patient care. The findings highlight the need for healthcare services to instigate strategies that support patients who have experienced acute deterioration and MET encounter.

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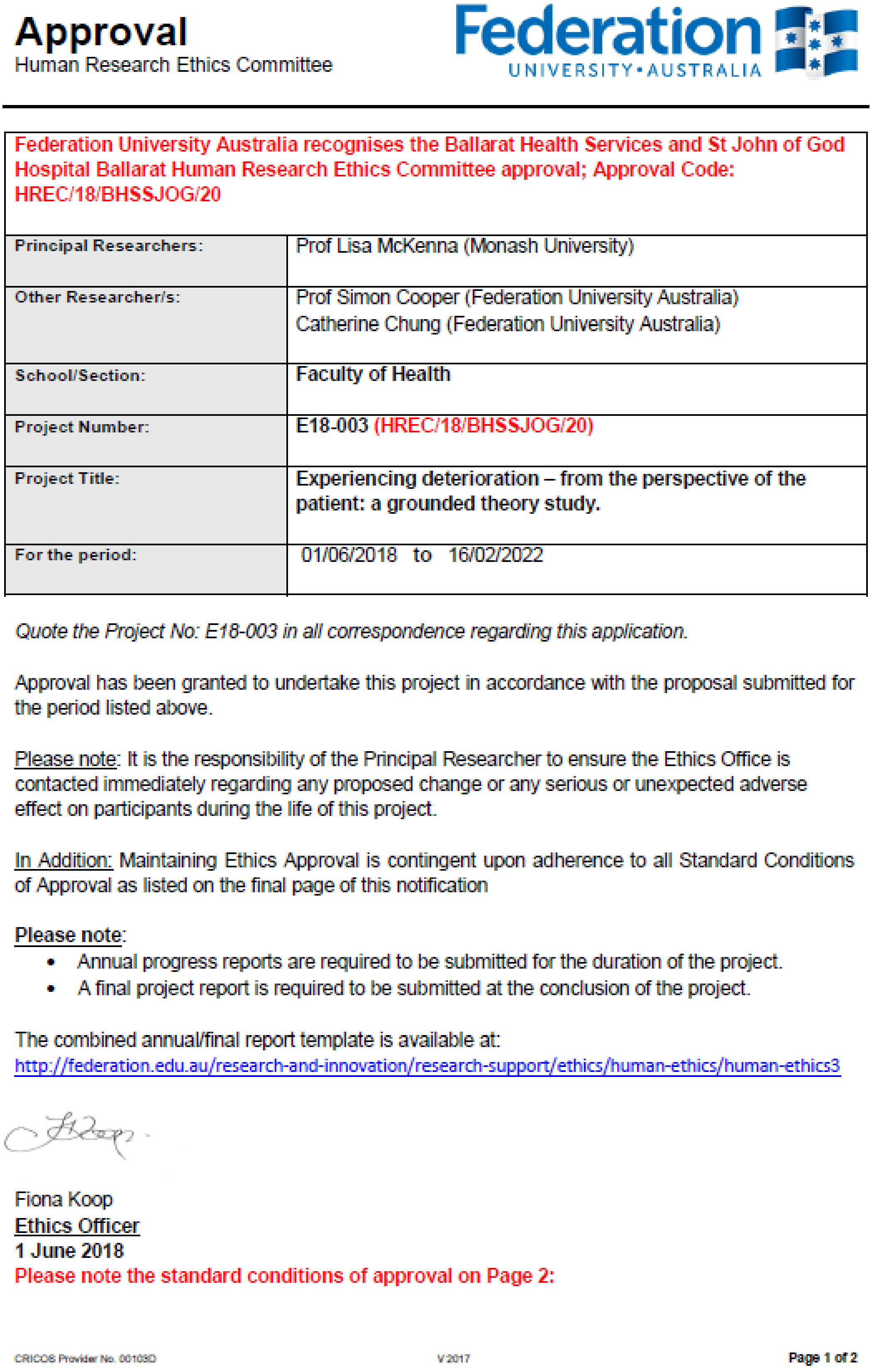
APPENDICES

Appendix 1a – Ethical Approval from Federation University



Approval
Human Research Ethics Committee

Federation UNIVERSITY • AUSTRALIA

Federation University Australia recognises the Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee approval; Approval Code: HREC/18/BHSSJOG/20

Principal Researchers:	Prof Lisa McKenna (Monash University)
Other Researcher/s:	Prof Simon Cooper (Federation University Australia) Catherine Chung (Federation University Australia)
School/Section:	Faculty of Health
Project Number:	E18-003 (HREC/18/BHSSJOG/20)
Project Title:	**Experiencing deterioration – from the perspective of the patient: a grounded theory study.**
For the period:	01/06/2018 to 16/02/2022

Quote the Project No: E18-003 in all correspondence regarding this application.

Approval has been granted to undertake this project in accordance with the proposal submitted for the period listed above.

Please note: It is the responsibility of the Principal Researcher to ensure the Ethics Office is contacted immediately regarding any proposed change or any serious or unexpected adverse effect on participants during the life of this project.

In Addition: Maintaining Ethics Approval is contingent upon adherence to all Standard Conditions of Approval as listed on the final page of this notification

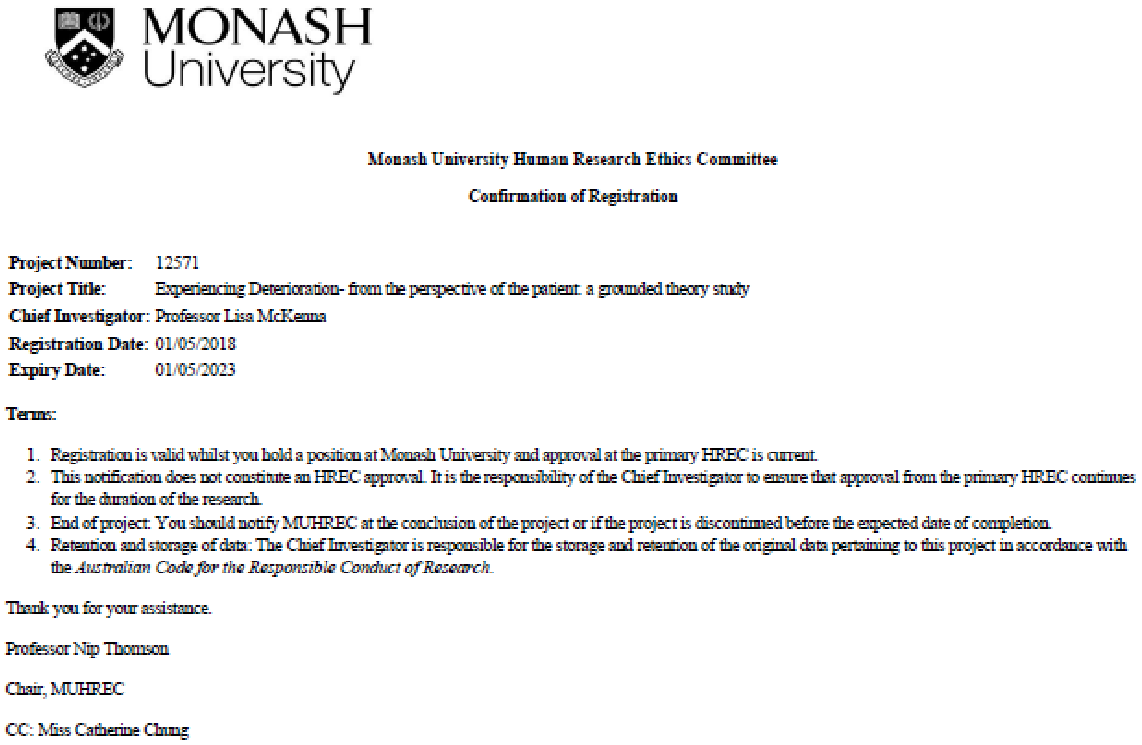
Please note:
- Annual progress reports are required to be submitted for the duration of the project.
- A final project report is required to be submitted at the conclusion of the project.

The combined annual/final report template is available at:
http://federation.edu.au/research-and-innovation/research-support/ethics/human-ethics/human-ethics3

Fiona Koop
Ethics Officer
1 June 2018
Please note the standard conditions of approval on Page 2:

CRICOS Provider No. 00103D V 2017 **Page 1 of 2**

Appendix 1b – Confirmation of Registration from Monash University



MONASH University

Monash University Human Research Ethics Committee

Confirmation of Registration

Project Number: 12571
Project Title: Experiencing Deterioration- from the perspective of the patient: a grounded theory study
Chief Investigator: Professor Lisa McKenna
Registration Date: 01/05/2018
Expiry Date: 01/05/2023

Terms:

1. Registration is valid whilst you hold a position at Monash University and approval at the primary HREC is current.
2. This notification does not constitute an HREC approval. It is the responsibility of the Chief Investigator to ensure that approval from the primary HREC continues for the duration of the research.
3. End of project: You should notify MUHREC at the conclusion of the project or if the project is discontinued before the expected date of completion.
4. Retention and storage of data: The Chief Investigator is responsible for the storage and retention of the original data pertaining to this project in accordance with the *Australian Code for the Responsible Conduct of Research*.

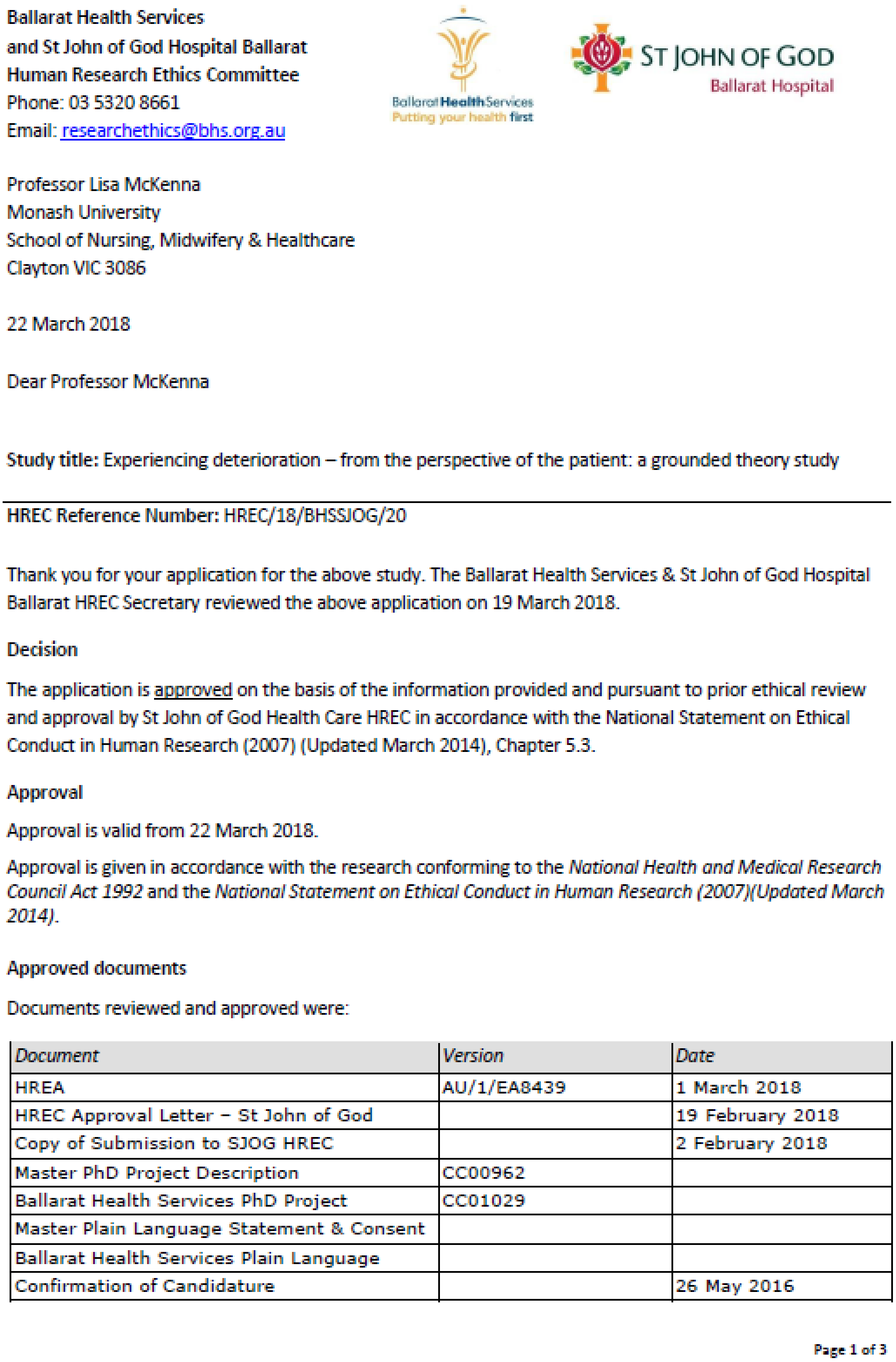
Thank you for your assistance.

Professor Nip Thomson

Chair, MUHREC

CC: Miss Catherine Chung

Appendix 1c - Ethical Approval from Ballarat Health Service



Ballarat Health Services
and St John of God Hospital Ballarat
Human Research Ethics Committee
Phone: 03 5320 8661
Email: researchethics@bhs.org.au

Professor Lisa McKenna
Monash University
School of Nursing, Midwifery & Healthcare
Clayton VIC 3086

22 March 2018

Dear Professor McKenna

Study title: Experiencing deterioration – from the perspective of the patient: a grounded theory study

---

HREC Reference Number: HREC/18/BHSSJOG/20

Thank you for your application for the above study. The Ballarat Health Services & St John of God Hospital Ballarat HREC Secretary reviewed the above application on 19 March 2018.

Decision

The application is approved on the basis of the information provided and pursuant to prior ethical review and approval by St John of God Health Care HREC in accordance with the National Statement on Ethical Conduct in Human Research (2007) (Updated March 2014), Chapter 5.3.

Approval

Approval is valid from 22 March 2018.

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research (2007)(Updated March 2014)*.

Approved documents

Documents reviewed and approved were:

Document	*Version*	*Date*
HREA	AU/1/EA8439	1 March 2018
HREC Approval Letter – St John of God		19 February 2018
Copy of Submission to SJOG HREC		2 February 2018
Master PhD Project Description	CC00962	
Ballarat Health Services PhD Project	CC01029	
Master Plain Language Statement & Consent		
Ballarat Health Services Plain Language		
Confirmation of Candidature		26 May 2016

Conditions of Approval

1. SSA authorisation is required at all sites participating in the study. SSA must be authorised at a site before the research project can commence. The completed Site-Specific Assessment Form and a copy of this ethics approval letter must be submitted to the Research Governance Officer for authorisation. This applies to each site participating in the research.

2. The project must be conducted in accordance with the approved application, including any conditions and amendments that have been approved. You must comply with all of the conditions imposed by the HREC, and any subsequent conditions that the HREC may require.

3. You must report immediately anything which might affect ethical acceptance of your project, including:

   - Adverse effects on participants;
   - Significant unforeseen events;
   - Other matters that might affect continued ethical acceptability of the project.

4. Any changes to the protocol must be submitted to the HREC for approval and should be accompanied by a summary outlining the reasons for the change together with an indication of any ethical implications. Two copies of amended documents must be provided: one with the amended version number or date clearly stated in the footer and another clearly highlighting the amended text.

5. The HREC should be advised of the actual commencement date of the project. If an extension is required beyond the approved end date of the project, a request for extension should be submitted, allowing sufficient time for its consideration by the committee. Extensions cannot be granted retrospectively.

6. If changes are to be made to the project's personnel, a Researcher Declaration form should be submitted for approval.

7. A Progress Report must be provided by the due date specified each year for the project to have continuing approval. The annual progress report is due on the 30th April each year.

8. A Final Progress Report must be provided at the conclusion of the project.

9. If, for any reason, the project does not proceed or is discontinued, you must advise the committee in writing, using a Progress Report form.

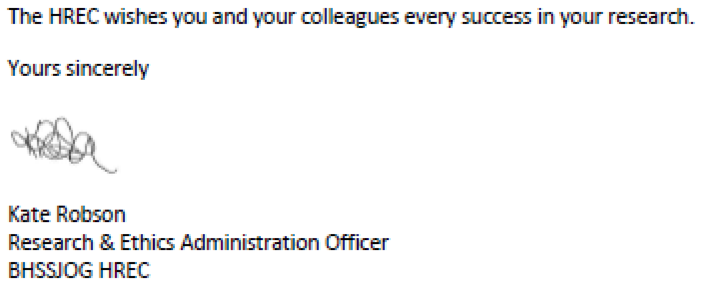
10. You must advise the HREC immediately, in writing, if any complaint is made about the conduct of the project.

11. You must notify the Ethics Office of any changes in contact details including address, phone number and email address.

12. The HREC may conduct random audits and / or require additional reports concerning the research project.

13. The HREC encourages the publication of results of the research in a discipline appropriate manner. Publications should provide evidence of the contribution that participants, researchers, funding sources and the organisations have made.

Failure to comply with the *National Statement on Ethical Conduct in Human Research* (2007 –Updated May 2015) and with the conditions of approval may result in suspension or withdrawal of approval.

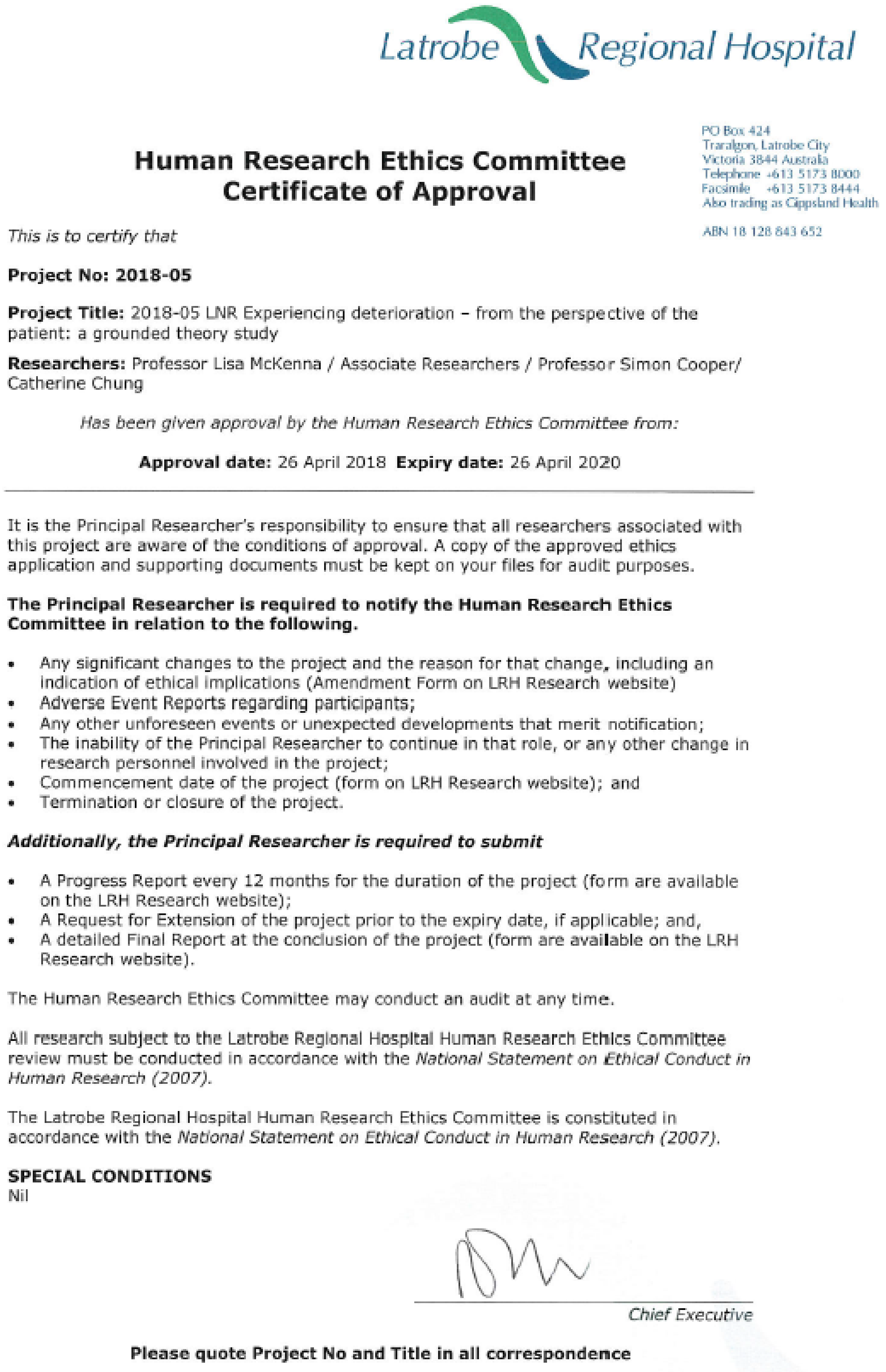


The HREC wishes you and your colleagues every success in your research.

Yours sincerely

Kate Robson
Research & Ethics Administration Officer
BHSSJOG HREC

Appendix 1d - Ethical Approval from Latrobe Regional Hospital



Latrobe Regional Hospital

PO Box 424
Traralgon, Latrobe City
Victoria 3844 Australia
Telephone +613 5173 8000
Facsimile +613 5173 8444
Also trading as Gippsland Health

ABN 18 128 843 652

Human Research Ethics Committee
Certificate of Approval

This is to certify that

Project No: 2018-05

Project Title: 2018-05 LNR Experiencing deterioration – from the perspective of the patient: a grounded theory study

Researchers: Professor Lisa McKenna / Associate Researchers / Professor Simon Cooper/ Catherine Chung

Has been given approval by the Human Research Ethics Committee from:

Approval date: 26 April 2018 **Expiry date:** 26 April 2020

It is the Principal Researcher's responsibility to ensure that all researchers associated with this project are aware of the conditions of approval. A copy of the approved ethics application and supporting documents must be kept on your files for audit purposes.

The Principal Researcher is required to notify the Human Research Ethics Committee in relation to the following.

- Any significant changes to the project and the reason for that change, including an indication of ethical implications (Amendment Form on LRH Research website)
- Adverse Event Reports regarding participants;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- Commencement date of the project (form on LRH Research website); and
- Termination or closure of the project.

Additionally, the Principal Researcher is required to submit

- A Progress Report every 12 months for the duration of the project (form are available on the LRH Research website);
- A Request for Extension of the project prior to the expiry date, if applicable; and,
- A detailed Final Report at the conclusion of the project (form are available on the LRH Research website).

The Human Research Ethics Committee may conduct an audit at any time.

All research subject to the Latrobe Regional Hospital Human Research Ethics Committee review must be conducted in accordance with the *National Statement on Ethical Conduct in Human Research (2007).*

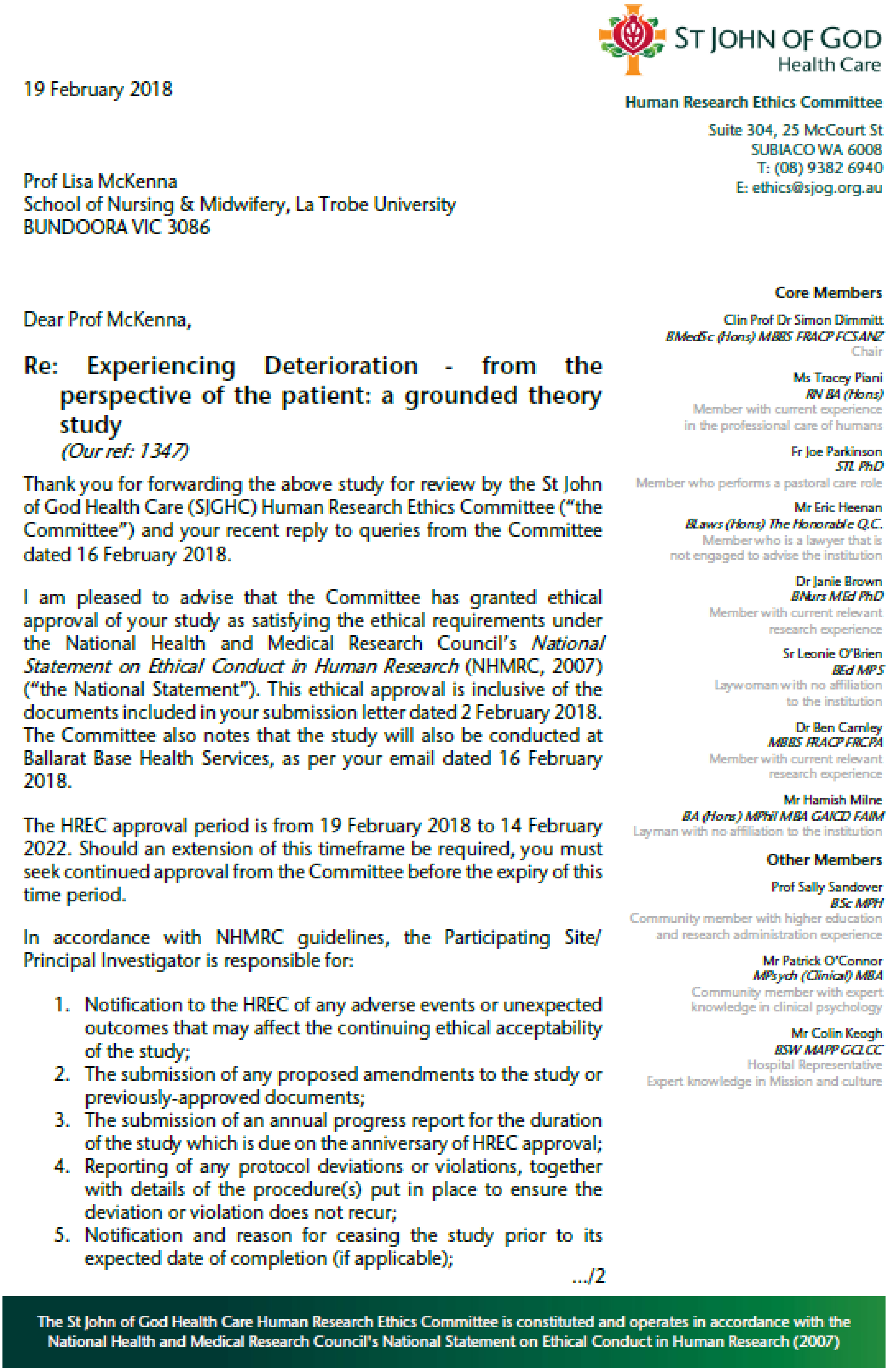
The Latrobe Regional Hospital Human Research Ethics Committee is constituted in accordance with the *National Statement on Ethical Conduct in Human Research (2007).*

SPECIAL CONDITIONS
Nil

Chief Executive

Please quote Project No and Title in all correspondence

Appendix 1e - Ethical Approval from St John of God Health Care



ST JOHN OF GOD
Health Care

Human Research Ethics Committee

Suite 304, 25 McCourt St
SUBIACO WA 6008
T: (08) 9382 6940
E: ethics@sjog.org.au

19 February 2018

Prof Lisa McKenna
School of Nursing & Midwifery, La Trobe University
BUNDOORA VIC 3086

Dear Prof McKenna,

Re: Experiencing Deterioration - from the perspective of the patient: a grounded theory study
(Our ref: 1347)

Thank you for forwarding the above study for review by the St John of God Health Care (SJGHC) Human Research Ethics Committee ("the Committee") and your recent reply to queries from the Committee dated 16 February 2018.

I am pleased to advise that the Committee has granted ethical approval of your study as satisfying the ethical requirements under the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* (NHMRC, 2007) ("the National Statement"). This ethical approval is inclusive of the documents included in your submission letter dated 2 February 2018. The Committee also notes that the study will also be conducted at Ballarat Base Health Services, as per your email dated 16 February 2018.

The HREC approval period is from 19 February 2018 to 14 February 2022. Should an extension of this timeframe be required, you must seek continued approval from the Committee before the expiry of this time period.

In accordance with NHMRC guidelines, the Participating Site/ Principal Investigator is responsible for:

1. Notification to the HREC of any adverse events or unexpected outcomes that may affect the continuing ethical acceptability of the study;
2. The submission of any proposed amendments to the study or previously-approved documents;
3. The submission of an annual progress report for the duration of the study which is due on the anniversary of HREC approval;
4. Reporting of any protocol deviations or violations, together with details of the procedure(s) put in place to ensure the deviation or violation does not recur;
5. Notification and reason for ceasing the study prior to its expected date of completion (if applicable);

.../2

The St John of God Health Care Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007)

6. The submission of a final report and translation of results (including publications) upon completion of the study.

You are reminded that this letter constitutes ethical approval only. You must not commence this research at SJGHC until separate authorisation in writing has been obtained.

I wish you well with your research.

Yours sincerely,

Clinical Professor Dr Simon Dimmitt
Chairman
St John of God Health Care Human Research Ethics Committee

cc. Catherine Chung, Federation University (via email)
cc. Lisa Norman, CEO, SJG Berwick Hospital (via email)

Appendix 2 – Patient Inclusion & Exclusion Check List

Researcher's
Details:
Catherine Chung
Phone:
0406 318 775
Email: catherine.chung@federation.edu.au

Patient Inclusion & Exclusion Check List

The purpose of this checklist is to determine if a patient who has experienced a **Medical Emergency Team (MET) review** is eligible to participate in a PhD research project. Once completed, this form is to be given to the researcher, Catherine Chung.

Patient Inclusion/Exclusion Criteria	Yes	No
Is the patient 18 years old or over?		
Are they an obstetric patient?		
Is the patient admitted to a mental health unit *OR* to mental health team?		
Did the MET review last for 10 min or longer?		

During the MET review what was the patients' conscious state assessed as?

____

Patient's name:____**DOB:** ____________

Patient's hospital ID:________________________**Date of Admission:** _____________

Reason for Hospital admission: ____

Reason for MET review: ____

What day of admission did the MET call occur? ________________________________

Ward:_____________________________________**Bed number:** __________________

Appendix 3a – Plain Language Information Statement (Ballarat Health Service)

Ballarat**Health**Services
Putting your health **first**

Plain Language Information Statement

My name is Catherine Chung and I am conducting a research project with Professor Lisa McKenna and Professor Simon Cooper from the School of Nursing, Midwifery and Healthcare, Federation University. I am working towards a Doctor of Philosophy (PhD) at Federation University.

You are invited to take part in this study because you have experienced a recent change in your health that required an emergency response. Please read this Plain language statement in full before deciding whether to participate in this research. If you would like further information regarding any aspect of this research, you are encouraged to contact the researchers via the phone numbers or email addresses listed below.

Ballarat Base Health Service is participating in research to explore the patient's experiences during acute deterioration of their own physiological conditions resulting in a medical emergency team (MET) call. You are invited to participate in **two (2)** 30-60 minute sessions where your experience will be explored.

1. *Why were you chosen to participate in the research interviews?*

We are interested in understanding your experience of this event. You are invited to participate by undertaking a semi-structured interview that will take between 30-60 minutes. Your experiences and thoughts will generate information about patient experiences, which will help professionals to better care for patients. Consenting to participate in the project is voluntary. The consent process involves signing and returning the consent form. You have the right to withdraw from further participation at any stage of the data collection process, and this will not affect your care. However, it will NOT be possible to withdraw data once collected, as data will be de-identified for analysis.

2. *What does participation in this research involve?*

Each session will take approximately 30-60 minutes. The sessions will occur at the following periods: within seven (7) days of the health event and between three (3) to six (6) months after the health event. If the researcher requires further information or clarification of any issues discussed, the participant may be contacted at a later date for a further interview. Your participation in this research is voluntary and participants can refuse to answer any interview questions if they are feeling uncomfortable or distressed. A mutually agreeable time and sufficiently safe place will be arranged for the interview to be conducted once consent is obtained.

3. *What are the possible benefits for taking part?*

You may not personally receive any benefit from participating in the study, other than the opportunity to talk about a significant health event. However, detailed findings of patient experiences of acute deterioration within the hospital setting will inform education and training to support patient care. It is anticipated that the findings of this research will positively influence the care and subsequent experience a patient may have during acute deterioration of their condition.

4. *What are the possible risks and disadvantages of taking part?*

Should participants become emotionally distressed during any of the interview sessions, immediate support will be provided by the researcher and appropriate referral to a counsellor for debrief and support.

Counselling service	Referral	Cost	Contact Number	Address
Latrobe Community Health Service	Researcher or Self-referral	No cost	1800 242 698	81/87 Buckley St, Morwell
CatholicCare Counselling Service, Gippsland	Researcher or Self-referral	Means tested care fee	(03) 56622 1188	52 MacArthur St, Sale
Life Line	No referral required	No cost	13 11 14	Phone counselling

Participation in this research is voluntary and participants can refuse to answer any questions if they are feeling uncomfortable or distressed. Participation in this project is justified by the potential to enhance the quality of care to acutely deteriorating patients within the hospital setting.

5. *What will happen to information about me?*

Confidentiality: All participants in the project will be de-identified once data collection commences and transcription occurs.

Secure storage of data: All data will physically be stored in a locked cabinet at all times when not in use by the researchers. Data stored on computer devices will be kept under password-protected files. After completion of this study, all information concerning this research will be stored permanently. It will be retained in Federation central repository or distribution system as per Federation University policy.

6. Payment

Payment is not applicable in this study.

7. Consent

Personnel invited to participate in this research will be required to sign a consent form. Participation is voluntary and participants may decline to participate without fear of consequences.

8. *Who has reviewed this research project?*

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

The St John of God Health Care Human Research Ethics Committee has given ethical approval for the conduct of this study. If you have any concerns or complaints regarding this study, you can contact the Executive Officer of the Committee (telephone number (08) 9382 6940) on a confidential basis. Your concerns will be drawn to the attention of the Committee that is monitoring the study.

The Human Research Ethics Committee of Latrobe Regional Hospital and Central Gippsland Health Service has approved the ethical aspects of this research project.

The Human Research Ethics Committee of Ballarat Health Care has approved the ethical aspects of this research project.

Research Results

If you would like to be informed of the aggregate research findings, please contact Catherine Chung on 0406 318 775 or email: catherine.chung@federation.edu.au

9. *Further information and who to contact*

If you would like further information concerning this project, or if you have any problems that may be related to your involvement in the project, you can contact the researcher or the executive officer below.

Research contact person

Name	Professor Simon Cooper
Position	Professor Federation University
Telephone	03 5122 8032
Email	s.cooper@federation.edu.au

If you have any concerns or complaints regarding this study, please contact the local site representative on a confidential basis.

Complaints contact person (Latrobe Regional Hospital and Central Gippsland Health Service)

Name	Catherine Wilkes
Position	Manager, Human Research Ethics Committees
Telephone	(03) 51738554
Email	hrec@lrh.com.au

Complaints contact person (St John of God Health Care)

Name	Ms Gerette De Jesus
Position	Executive Officer, St John of God Human Research Ethics Committee
Telephone	(08) 9382 6940
Email	Gorette.de.jesus@sjog.org.au

Complaints contact person (Ballarat Base Health Service)

Name	Diane Clingin
Position	Research Quality & Integrity Officer, Ballarat Health Services
Telephone	03 5320 8661
Email	researchethics@bhs.org.au

Appendix 3b – Participant Consent Form (Ballarat Health Service)

Ballarat Health Services
Putting your health first

Participant Consent Form

Title: Experiencing acute deterioration – from the perspective of the patient: a grounded theory study.

NOTE: **This consent form will remain with the Federation University researcher for their records.**

I agree to take part in the Federation University research project specified above. I have had the project explained to me and I have read the plain language statement, which I keep for my records. I have been given an opportunity to ask questions in relation to the study. I understand that agreeing to take part means that:

I agree to be interviewed by the researcher	☐ Yes ☐ No
I agree to make myself available for a second interview	☐ Yes ☐ No
I agree to allow the interview to be audio-taped	☐ Yes ☐ No
I have a clear understanding of what the study means	☐ Yes ☐ No

I understand that my participation is voluntary, that I can choose not to participate in the project without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

I understand that data from the **audio taped interview** will be kept in a secure storage and accessible to the research team. I also understand that the data will be stored permanently. It will be retained in Federation central repository or distribution system as per Federation University policy.

Participant's name: ____

Signature: ______________________ **Date:** ____________________

Appendix 4a – Plain Language Information Statement (Latrobe Regional Hospital & Central Gippsland Health Service)

Plain Language Information Statement

My name is Catherine Chung and I am conducting a research project with Professor Lisa McKenna and Professor Simon Cooper from the School of Nursing, Midwifery and Healthcare, Federation University. I am working towards a Doctor of Philosophy (PhD) at Federation University.

You are invited to take part in this study because you have experienced a recent change in your health that required an emergency response. Please read this Plain language statement in full before deciding whether to participate in this research. If you would like further information regarding any aspect of this research, you are encouraged to contact the researchers via the phone numbers or email addresses listed below.

Latrobe Regional Hospital and Central Gippsland Health Service is participating in research to explore the patient's experiences during acute deterioration of their own physiological conditions resulting in a medical emergency team (MET) call. You are invited to participate in two (2) 30-60 minute sessions where your experience will be explored.

1. *Why were you chosen to participate in the research interviews?*

We are interested in understanding your experience of this event. You are invited to participate by undertaking a semi-structured interview that will take between 30-50 minutes. Your experiences and thoughts will generate information about patient experiences, which will help professionals to better care for patients. Consenting to participate in the project is voluntary. The consent process involves signing and returning the consent form. You have the right to withdraw from further participation at any stage of the data collection process, and this will not affect your care. However, it will NOT be possible to withdraw data once collected, as data will be de-identified for analysis.

2. *What does participation in this research involve?*

Each session will take approximately 30-60 minutes. The sessions will occur at the following periods: when the participant has recovered sufficiently from their MET review and has the capacity to consent and between three (3) to six (6) months after the health event. If the researcher requires further information or clarification of any issues discussed, the participant may be contacted at a later date for a further interview. Your participation in this research is voluntary and participants can refuse to answer any interview questions if they are feeling uncomfortable or distressed. A mutually agreeable time and sufficiently safe place will be arranged for the interview to be conducted once consent is obtained.

3. *What are the possible benefits for taking part?*

You may not personally receive any benefit from participating in the study, other than the opportunity to talk about a significant health event. However, detailed findings of patient experiences of acute deterioration within the hospital setting will inform education and training to support patient care. It is anticipated that the findings of this research will positively influence the care and subsequent experience a patient may have during acute deterioration of their condition.

4. *What are the possible risks and disadvantages of taking part?*

The first interview will take place by the bed side or in a suitable area on the ward, unit or department to ensure the patient's privacy, safety and access to medical treatment.
Should participants become emotionally distressed during any of the interview sessions, immediate support will be provided by the researcher and appropriate referral to a counsellor for debrief and support.

Counselling service	Referral	Cost	Contact Number	Address
Latrobe Community Health Service	Researcher or Self-referral	No cost	1800 242 698	81/87 Buckley St, Morwell
CatholicCare Counselling Service, Gippsland	Researcher or Self-referral	Means tested care fee	(03) 56622 1188	52 MacArthur St, Sale
Life Line	No referral required	No cost	13 11 14	Phone counselling

Participation in this research is voluntary and participants can refuse to answer any questions if they are feeling uncomfortable or distressed. Participation in this project is justified by the potential to enhance the quality of care to acutely deteriorating patients within the hospital setting.

5. *What will happen to information about me?*

Confidentiality: All participants in the project will be de-identified once data collection commences and transcription occurs.

Secure storage of data: All data will physically be stored in a locked cabinet at all times when not in use by the researchers. Data stored on computer devices will be kept under password-protected files. After completion of this study, all information concerning this research will be stored permanently. It will be retained in Federation central repository or distribution system as per Federation University policy.

6. Payment

Payment is not applicable in this study.

7. Consent

Personnel invited to participate in this research will be required to sign a consent form. Participation is voluntary and participants may decline to participate without fear of consequences.

8. *Who has reviewed this research project?*

The Human Research Ethics committee of Latrobe Regional Hospital and Central Gippsland Health Service has approved the ethical aspects of this research project. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Research Results

If you would like to be informed of the aggregate research findings, please contact Catherine Chung on 0406 318 775 or email: catherine.chung@federation.edu.au

9. *Further information and who to contact*

If you would like further information concerning this project, or if you have any problems that may be related to your involvement in the project, you can contact the researcher or the executive officer below.

Research contact person

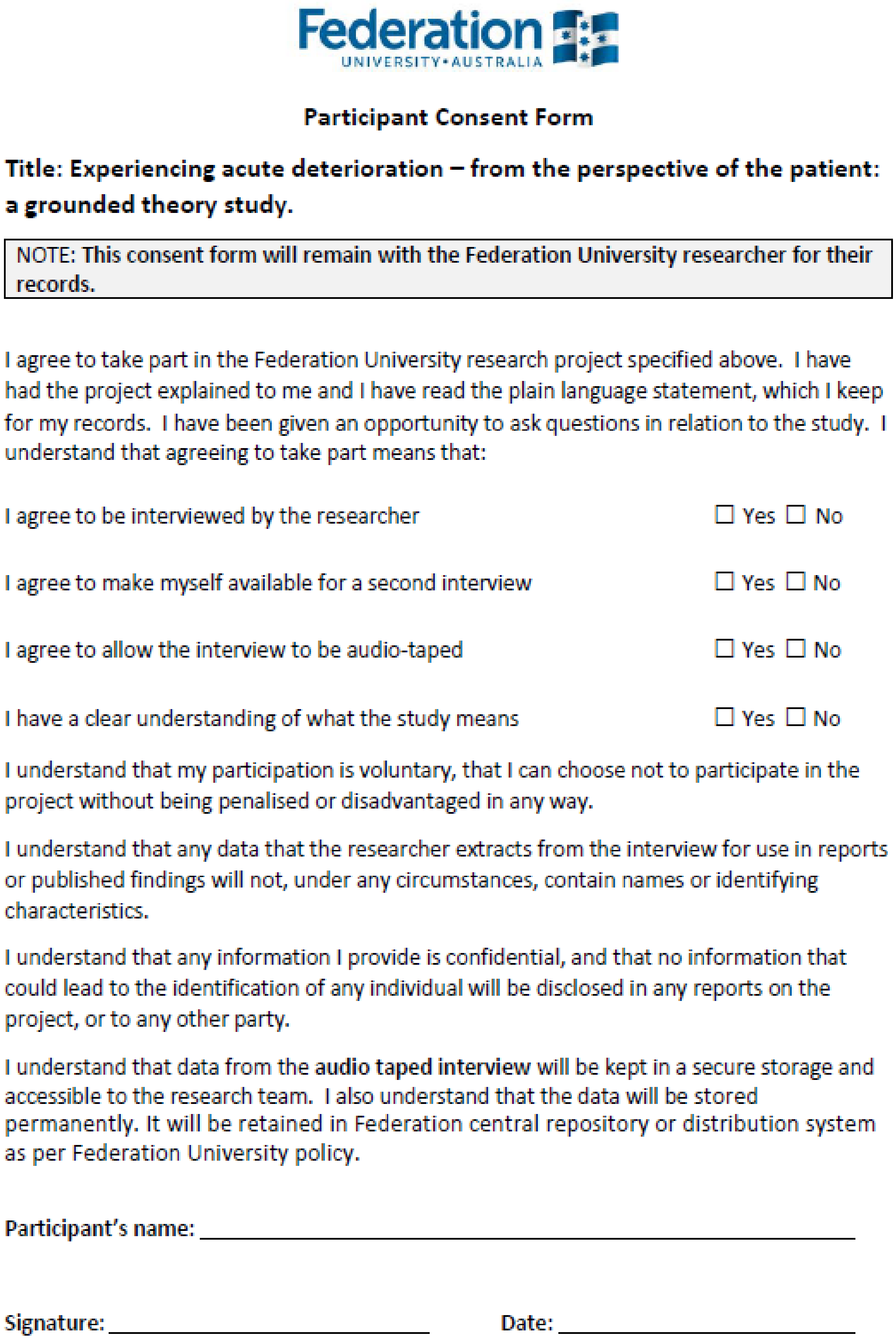
Name	Professor Simon Cooper
Position	Professor Federation University
Telephone	03 5122 8032
Email	s.cooper@federation.edu.au

If you have any concerns or complaints regarding this study, please contact the local site representative on a confidential basis.

Complaints contact person (Latrobe Regional Hospital)

Name	Catherine Wilkes
Position	Manager, Human Research Ethics Committees
Telephone	(03) 51738554
Email	hrec@lrh.com.au

Appendix 4b – Consent Form (Latrobe Regional Hospital & Central Gippsland Health Service)



Federation
UNIVERSITY•AUSTRALIA

Participant Consent Form

Title: Experiencing acute deterioration – from the perspective of the patient: a grounded theory study.

NOTE: **This consent form will remain with the Federation University researcher for their records.**

I agree to take part in the Federation University research project specified above. I have had the project explained to me and I have read the plain language statement, which I keep for my records. I have been given an opportunity to ask questions in relation to the study. I understand that agreeing to take part means that:

I agree to be interviewed by the researcher ☐ Yes ☐ No

I agree to make myself available for a second interview ☐ Yes ☐ No

I agree to allow the interview to be audio-taped ☐ Yes ☐ No

I have a clear understanding of what the study means ☐ Yes ☐ No

I understand that my participation is voluntary, that I can choose not to participate in the project without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

I understand that data from the **audio taped interview** will be kept in a secure storage and accessible to the research team. I also understand that the data will be stored permanently. It will be retained in Federation central repository or distribution system as per Federation University policy.

Participant's name: ______________________________

Signature: ____________________ **Date:** ____________________

Appendix 5 – Interview Guide

Introduction

- Introduce Researcher
- Provide participant with a brief explanation of the study and reiterate the aim of the study
- Ensure the participant has read and understands the participant explanatory statement.
- Ensure the participant consent form has been signed.

Body of the Interview

I am interested to understand your experience of becoming unwell and needing to be cared for by the hospital's medical emergency response team. Can you describe for me your experience?

- Tell me about how you came to be in hospital?
- What is your understanding of the reason you were admitted to hospital and your management plan?
- While in hospital and before your medical emergency team (MET) review, when, if at all, did you first experience or notice that your condition had changed? If so, what was it like? If you recall, what were you thinking then? Did anyone or anything influence your actions?
- What happened next?
- Could you describe the events that led up to your MET review?
- Can you tell me about your experience of being cared for by a MET? What were your thoughts and feelings during this time? Did anyone or anything influence your actions?
- Could I ask you to describe the most important part of your experience?
- What happened next?
- How would you describe your condition before, during and after your Met review?
- As you look back on your experience, do you have any advice for the MET?
- Looking back, do you have any advice for a patient being who experiences acute clinical deterioration and MET review?
- Is there something else you think I should know to understand your experience better?

Conclusion

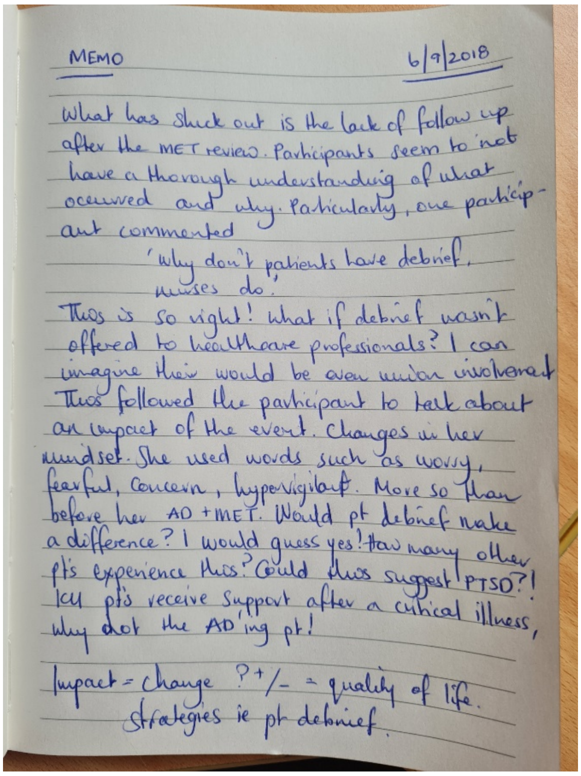
Is there anything you would like to ask me?

May I have your permission to contact you again should I require further clarification of the data?

Would you like a summary of the study when it's completed?

Thank you for your participation.

Appendix 6 – Examples of Analytical Memos



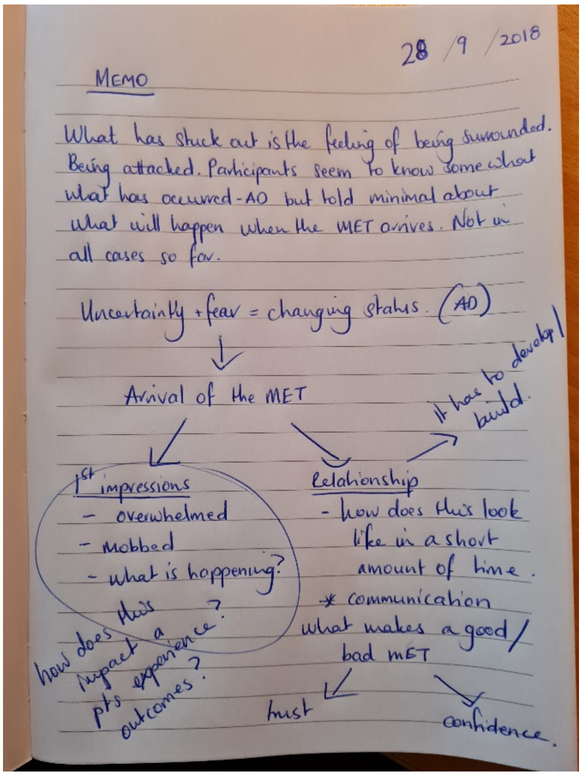
MEMO 6/9/2018

What has stuck out is the lack of follow up after the MET review. Participants seem to not have a thorough understanding of what occurred and why. Particularly, one participant commented

'why don't patients have debrief, nurses do'.

This is so right! what if debrief wasn't offered to healthcare professionals? I can imagine their would be even union involvement. This followed the participant to talk about an impact of the event. Changes in her mindset. She used words such as worry, fearful, concern, hypervigilant. More so than before her AD + MET. Would pt debrief make a difference? I would guess yes! How many other pt's experience this? Could this suggest PTSD?! ICU pt's receive support after a critical illness, why not the AD'ing pt!

Impact = change ? +/– = quality of life.
strategies ie pt debrief.



MEMO 28/9/2018

What has stuck out is the feeling of being surrounded. Being attacked. Participants seem to know somewhat what has occurred - AO but told minimal about what will happen when the MET arrives. Not in all cases so far.

Uncertainty + fear = changing status. (AD)

↓

Arrival of the MET

1st impressions
- overwhelmed
- mobbed
- what is happening?

how does this impact a pts experience? outcomes?

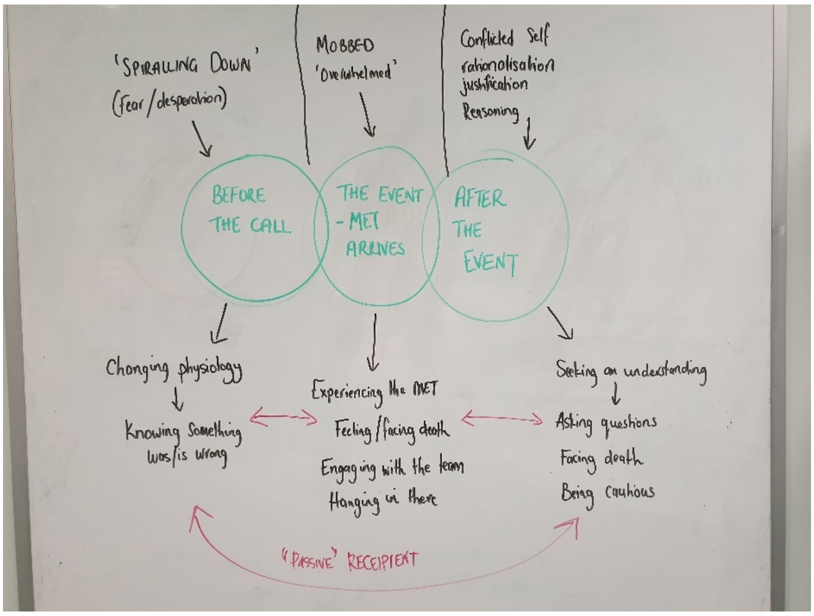
Relationship
- how does this look like in a short amount of time.

it has to develop/build.

* communication
what makes a good/bad MET

trust

confidence.



Appendix 7 – Methodological Journal

Field Note 1:

Sarah became upset (her voiced changed & she started to cry) when speaking about the physical pain caused in ICU when being moved. She also showed me the bruises on her L) arm from multiple attempts to draw blood during her MET call. She asked me why at the time did her arm feel numb/cold. She said she had asked the nurse looking after her but didn't understand the answer. Sarah was eager to talk with me. She tried to sign the consent form before reading through the plain language information statement (PLIS). I made sure she read the PLIS before signing. She wanted to tell me about her ICU stay after she was transferred to ICU after her MET review. She didn't have nice things to say. She said she they overdosed her on pain medication, and she couldn't understand why they didn't speak to her GP who would have been able to explain what medications she was taking and what she couldn't take.

Field Note 2:

Terry was welcoming & eager to share his story. He tried to sign the consent form without reading the PLIS. I explained the form and left his to read it before signing. During the interview he became emotional when he spoke about his realisation that he might not have survive. He talked about the pain it would cause his family, especially his daughter. He said he had a good life and accepts that his death might be near. He had oxygen via nasal cannulas and became breathless when he moved or spoke too quickly. He said oxygen saturations dropped when he wasn't on oxygen. He was very confident that he remembered all that occurred when he was being treated in the MET review. His daughter arrived during the interview and I felt he didn't want to say much more in front of her.

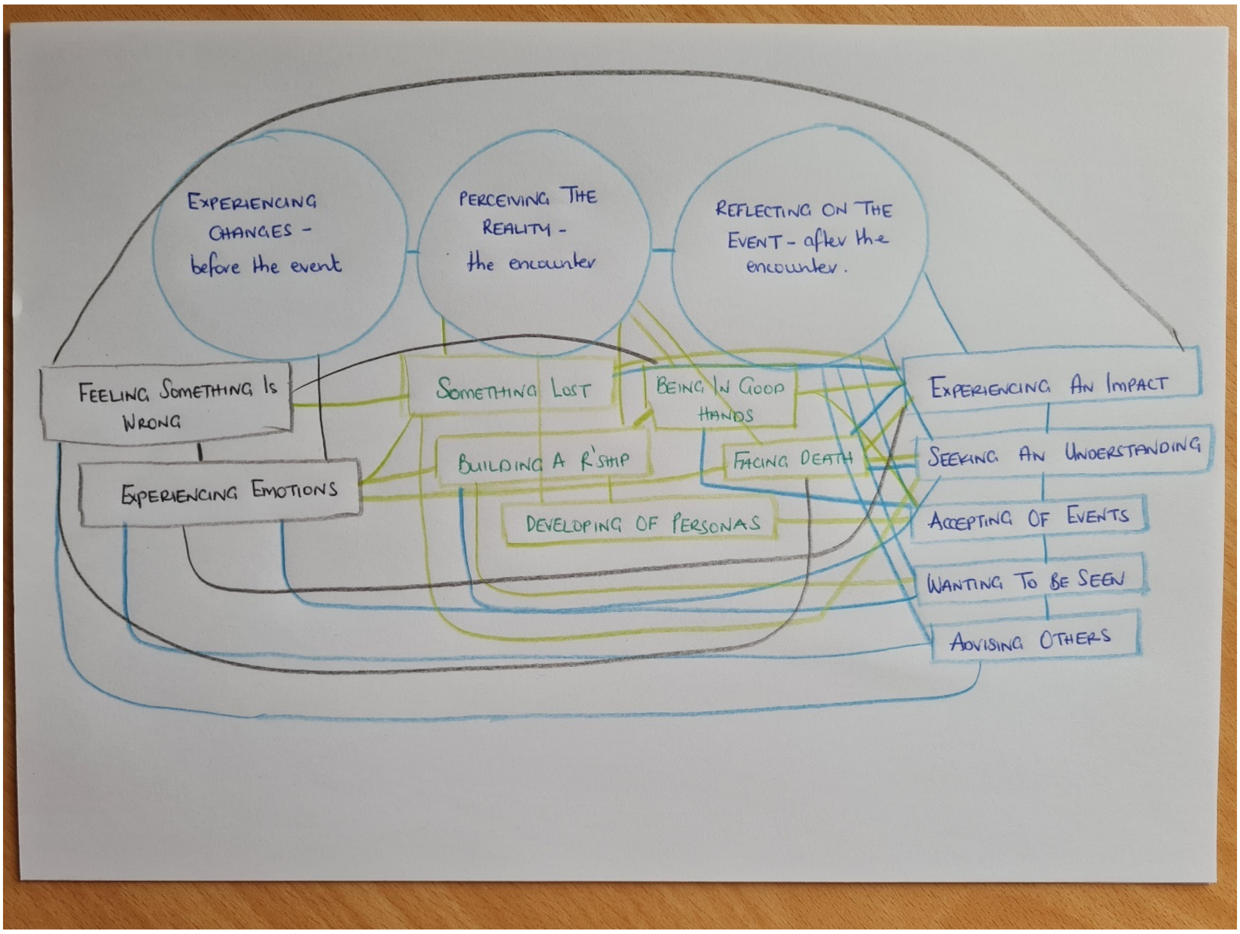
Field Note 3:

Kelly has a 9-month-old who was at the bedside with her husband during the interview. They are a blended family. During the interview, the patients was sitting up in the bed and playing with her baby while her husband got coffees. Kelly appeared tired with reddened areas under both her eyes, maybe a skin irritation. She was an HDU patient in an ICU bed and due for transfer to the ward that afternoon. During the interview she held eye contact and answered questions clearly while holding her baby. She appeared to understand the significance of her unexpected acute deterioration and MET review but was more concerned that her family, especially her husband was not informed about what happened. She told him the next day when he visited. She also expressed annoyance at the delay it caused her surgery because she has a young family she wanted to be home as soon as possible to be with her children.

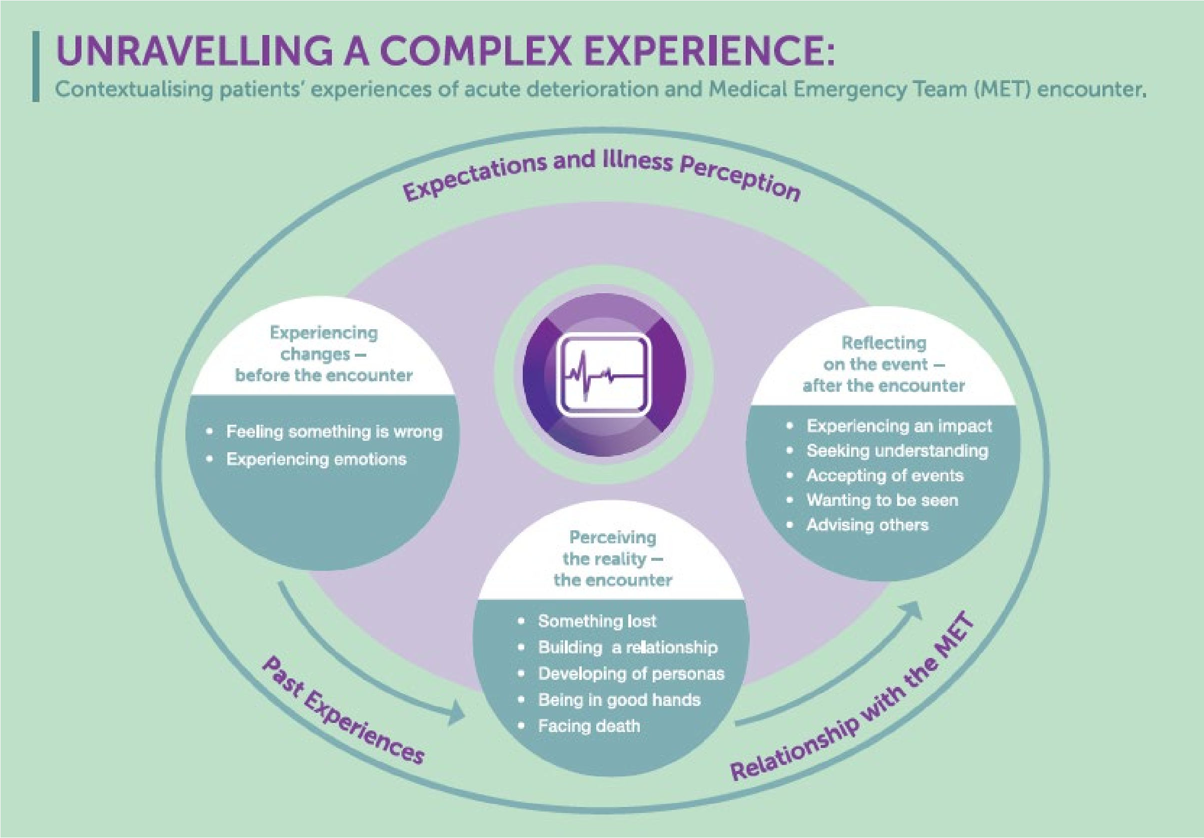
Field Note 4:

After I turned off the recorder Eric wanted to talk further, he didn't want what he said to be recorded because he hadn't told anyone before. During a previous acute deterioration, he recalls lying in a foetal position and feeling strange, like he was dying. He described quiet, no noise, nothing. He remembers darkness and feeling like he was drifting away. Something triggered him awake. He believes it was his subconscious saying her had too much to do in his life, the darkness went away. He was positive this was death but knew he can't die yet. Everything became normal again. He said this is the reason he is a positive thinker and way any deterioration after this he is not worried about. He knows he can come back from death if he thinks positively. After this experience he sat on the side of the bed, he had no pain, no sadness and instead he felt happy to be alive.

Appendix 8 – A Concept Map Illustrating Relationships Between Categories and Codes



Appendix 9 – Theoretical Model



UNRAVELLING A COMPLEX EXPERIENCE:

Contextualising patients' experiences of acute deterioration and Medical Emergency Team (MET) encounter.