The Lived Experiences of Survivors of Pre-Hospital Arrest Following Therapeutic Hypothermia

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Nursing

by

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ABSTRACT

In 2013, the American Heart Association estimated that 359,400 Americans experienced cardiac arrest and only 9.5% of those people survived. In the 2015 American Heart Association guidelines for Basic Life Support (BLS) and Advanced Cardiac Life Support (ACLS), therapeutic hypothermia (targeted temperature management) has been declared the gold standard of treatment after the return of spontaneous circulation (ROSC) when the patient has persistent coma. Some of these patients live, some don’t. For those at the bedside caring for therapeutic hypothermia patients, this leaves many unanswered questions.

The purpose of this study is to understand the lived experience of survivors of pre-hospital arrest treated with therapeutic hypothermia. Understanding this phenomenon will contribute to the science of nursing practice and assist those who provide direct care for the patients better understand the experience from the patient’s perspective as well as areas of care that may need to be reassessed and improved. The methodology that was utilized for this qualitative study was phenomenology.

A total of three participants were recruited for this study. There were two women and one man whose ages ranged from 51 to 69 years. Themes uncovered were: Loss of time, urgency to leave the hospital, physical changes, lack of end-of-life planning, cooperation and acknowledgement of own death. These findings can help bedside providers better understand the needs of the patient as well as the importance of discharge education and follow-up care.
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CHAPTER I
INTRODUCTION

Background and Significance

The American Heart Association defines cardiac arrest as the “abrupt loss of heart function in a person who may or may not have diagnosed heart disease” due to a malfunction of the heart’s electrical system (American Heart Association, 2017, para 1). Ventricular tachycardia (VT), ventricular fibrillation (VF), asystole, and pulseless electrical activity (PEA) are the lethal heart rhythms that are associated with cardiac arrest. Wachelder et al (2009) affirm that the brain experiences hypoxia during cardiac arrest that could cause diffuse ischemic-hypoxic injury. With return-of-spontaneous circulation (ROSC), post-resuscitation disease begins including post arrest brain injury, myocardial dysfunction, systemic ischemia or reperfusion response, as well as the initial pathology that caused the arrest (Beseda, Smith & Veenstra, 2014).

The idea of resuscitation of sudden death patients dates back as early as 1540 when Andreas Vesalius suggested that lives can be restored by breathing for them through an artificial airway (Cooper, Cooper & Cooper, 2006). This was augmented by William Tossach (1744) when he described breathing for another by forcing air into the lungs with his mouth to theirs. Closed chest cardiac massage was first successfully performed by Friedrich Maass in 1892 yet would not be further explored until Guy Knickerbocker rediscovered the success of chest compressions while researching defibrillation in dogs almost 60 years later (Taw, 1991). Paul Zoll was responsible for the first successful closed chest cardiac defibrillation in 1954 (Zoll, Linenthal, Gibson, Paul, Norman, 1956).
Cooper, Cooper and Cooper (2006) elucidate that initially, CPR was only performed by trained professionals that could only respond to inpatient cardiac arrest patients. Since most arrests happen outside of the hospital, in 1960, physicians staffed mobile intensive care ambulances until they realized that other medical personnel could perform the life-saving measures until they were able to reach a hospital. The authors confirm that the first CPR guidelines were published in 1960 and were then taught to non-medical personnel in 1970.

In 2013, the American Heart Association estimated that 359,400 Americans experienced cardiac arrest and only 9.5% of those people survived. In the 2015 American Heart Association guidelines for Basic Life Support (BLS) and Advanced Cardiac Life Support (ACLS), therapeutic hypothermia (currently named targeted temperature management) has been declared the gold standard of treatment after return of spontaneous circulation (ROSC) when the patient has persistent coma. Therapeutic hypothermia is used to slow the metabolic needs of the body in order to preserve neurologic function (Beseda et al., 2014).

A description of Baylor University Medical Center’s Therapeutic Hypothermia protocol is provided in the Critical Care Nurse Journal published by authors Beseda et al. (2014). The body is cooled to 32 to 34 degrees Celsius and maintained for approximately 24 hours. During this time, the patient is being sedated and medicated for pain to attempt to maintain the patient’s comfort during cooling. A pharmaceutical paralytic is also used in order to prevent shivering which is the body’s natural response when trying to get warm. Preventing shivering will keep the body’s metabolic needs reduced. Afterward, the body is slowly rewarmed to 37 degrees Celsius at an approximate rate of 0.25 degrees
an hour, usually taking between 12 and 20 hours. Patients’ vital signs are measured continuously throughout the process as well as the use of a BIS (bispectral) monitor to track the patient’s level of sedation. In this setting, hypothermia is considered therapeutic because it slows down the body’s metabolic processes so much that the brain swelling is reduced in hopes to retain the patient’s baseline neurological function (Beseda, Smith, & Veenstra, 2014).

Problem Statement

After cardiac arrest patients are resuscitated, some regain consciousness, while others don’t. Those that do not regain consciousness with ROSC, according to AHA 2015 guidelines, are to be treated with therapeutic hypothermia. When therapeutic hypothermia is implemented, patients experience a myriad of assessments, lab tests, procedures, exams, and receive a multitude of medications with the purpose of keeping them paralyzed, sedated, pain-free, and hemodynamically stable. Within a preset amount of time, the patient will be rewarmed and the paralytic medication, as well as the sedation, is stopped. Following rewarming, the patient will be assessed for, if any, neurological function post event.

Those that do recover neurological function are eventually discharged to home, rehab, or a long-term care facility (LTAC). The healthcare team that provided care during the critical phase of resuscitation and recovery are often left with questions of; what happened to that patient, how long did they live after discharge, what kinds of long-term health issues resulted from treatment, are they happy with their lives, do they wish their family had made a different decision, do they have advanced directives now, are they a Do Not Resuscitate (DNR) or a Full Code? If healthcare providers had answers to
these questions, perhaps it would help them address the areas in which the patient’s long-term quality of life can be enhanced during the acute recovery.

**Purpose of Study**

The purpose of this study was to understand the lived experience of survivors of pre-hospital arrest treated with therapeutic hypothermia. Understanding this phenomenon will contribute to the science of nursing practice. It will assist those who provide direct care for the patients a better understanding of the experience from the patient’s perspective as well as areas of care that may need to be reassessed and improved.

**Research Question**

The main question that was used to guide this study is: What is the meaning and significance of the lived experience of a survivor of pre-hospital arrest treated with therapeutic hypothermia, during the initial recovery period, and in their current day-to-day lives? The treatment phase will be defined as the hospital stay from event to discharge. Initial recovery will be the first three months after the event and current day-to-day lives is at the time of the interview.

**Summary**

This chapter provided a brief introduction to this research. Included is the purpose of the study as well as the research question which will guide this research. The next chapter will explore and discuss the current literature related to therapeutic hypothermia for the treatment of cardiac arrest.
CHAPTER II
LITERATURE REVIEW

A search for information pertaining to therapeutic hypothermia for cardiac arrest and survivors’ quality of life and lived experience began with a computerized review of the literature in CINHAL and Pub Med. There were zero articles found when “lived experience”, “cardiac arrest survivors”, and “therapeutic hypothermia” were searched together. A search for “lived experience” and “cardiac arrest” yielded three relevant studies, from 2002 to 2014. While there is sparse literature regarding the qualitative aspect of this population, there are many quantitative studies that address the quality of life (QoL) for patients who have survived cardiac arrest. This information can be very helpful in understanding clinical outcomes of these patients; however it does not give healthcare providers the full picture of the patients’ lives following resuscitation.

Quality of Life Measures

Quality of Life (QoL) has been measured in several different ways in many different studies, though there are some that are considered validated assessment tools. The SF-36 survey, which is part of the Rand Health Medical Outcomes Study, measures functional health using subscales for pain, general health, perceptions, mental health, physical functioning, emotional and physical roles, social functioning and vitality (Bunch, White, Khan & Packer, 2004; Wachelder et al, 2009). Other QoL assessment tools used include, but are not limited to: The New York Heart Association Classification (964), Fatigue Severity Scale (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989), The Barthel Index (Mahoney & Barthel, 1965), The Frenchay Activities Index (Holbrook & Skilbeck, 1983), Instrumental Activity Measure (Lawton & Brody, 1969), The
Nottingham Health Profile (Hunt, McKenna, McEwen, Williams, & Papp, 1981) and The Health Utilities Index Mark III System (Torrance & Feeny, 1986). Additionally, cognitive function post-arrest has been studied utilizing Mini Mental State Exam (Folstein et al., 1975), Cognitive Failures Questionnaire (Broadbent, Cooper, FitzGerald, & Parkes, 1982), Cerebral Performance Category Scale (Bond, 1975), and others. There are many questionnaires and assessment tools used to assess anxiety, depression and social interactions. There are even tools that measure caregiver strain (Wachelder et al, 2009).

There have been many tools developed to assess the ability of patients to perform ADLs, assess cognition, anxiety and social disposition but very few that address the lived experiences and perceptions of the patient. A systematic review of literature conducted by Elliott, Rodgers and Brett (2011) suggests that there is good evidence to support the claim that cardiac arrest survivors have an acceptable quality of life although it is not what it was before the cardiac arrest took place.

**Qualitative Studies**

Dickerson (2002) examined a group of cardiac arrest patients who had a placement of an internal defibrillator. For these patients, the reality of receiving a shock at any moment can induce persistent significant anxiety. Themes that emerge from this study included; losing control and dependence on technology. These patients were forced to realize their own mortality that made them feel very vulnerable and fragile.

Near death experiences in cardiac arrest patients as studied by Parnia, Spearpoint and Fenwick (2007) identified participants who stated they had a near death experience. The main themes identified through this study included: the point of no return, feeling
peace, feeling joy, seeing a bright light, losing awareness of the body, and finally, seeing deceased relatives. Some of these patients also can remember watching themselves be resuscitated and can recall very specific information about the event. This study concluded that survivors of cardiac arrest often “experience behavioral, cognitive and emotional disturbances that may begin soon after the cardiac arrest and persist for many years” (p 220).

A group of researchers from Sweden, Forslund, Zingmark, Jansson, Lundblad and Soderberg (2014), studied the lived experiences of patients who had an out-of-hospital arrest. These participants achieved ROSC and regained consciousness immediately afterward; therapeutic hypothermia was not indicated. The themes discovered in this study were returning to life and revaluing life. Subthemes were waking up and missing the whole picture, realizing it was not time to die, wondering why and seeking explanations, feeling ambiguous in relations, and wondering whether life will be the same. Many of these participants ask the “what if” questions that, had they been in another place or had their significant other not found them; how would that have changed the outcome of their story? Some participants also confessed to feeling guilty for making family and friends worry. These researchers discovered that these patients were searching for meaning regarding their arrest and wanted to make life changes accordingly. “Dying was easy and not frightening, but it made them explicitly aware that life is not endless” (p 468). Through this experience, the participants were led to reevaluate what was truly important in their lives.
Summary

While there are many ways to quantitatively measure the quality of life in patients that have experienced cardiac arrest, it does very little to help healthcare providers understand the lived experiences of these patients. Qualitative studies exist that discuss near death experiences, internal defibrillator placement and the meaning of cardiac arrest in this population yet there is paucity in the literature related to patients who have recovered from cardiac arrest following treatment with therapeutic hypothermia.
CHAPTER III
METHOD OF INQUIRY

The methodology that was utilized for this qualitative study was phenomenology. Phenomenological research is used when an author is attempting to describe the lived experience of an event in a person’s life from their perspective. Van Manen (1990) asserts that phenomenology is “not an empiric analytic science” (p. 21), but its interest is in “the human world as we find it” (p 18). On occasion referred to as human science, van Manen agrees with Dilthey in that phenomenology aims at understanding the meaning of human phenomena (p. 4).

Historical Foundations of Phenomenology

The word phenomenon has its origins in the Greek language, *phaenesthai*, which means to show itself or to appear (Moustakas, 1994). There have been many philosophers who have had their own estimation of what phenomenological research meant. The first inklings of this philosophy were in the 18th century with Immanuel Kant, Georg Hegel and Ernst Mach. The principle founder of Phenomenology was Edmund Husserl whose contribution came in the early 20th century (Beyer, 2015). Husserl’s idea of phenomenology is a philosophy of consciousness, to describe experiences without theoretical or metaphysical involvement (Internet Encyclopedia of Philosophy, n.d.). Others, such as Heidegger, Satre, and Merleau-Ponty, also made significant contributions to the understanding and interpretation of phenomenology.

Phenomenological Activities Related to This Study

Through hermeneutic phenomenology, van Manen (1990) offers a contemporary approach to research utilizing six activities. The first activity is *turning to a*
phenomenon which seriously interests us and commits us to the world. The subject should be something that the researcher is passionate about making sense of for his/her self as well as the rest of humanities’ understanding. This researcher’s interest in this subject came after many instances of caring for cardiac arrest patients who were treated with therapeutic hypothermia. Many of these patients didn’t survive, but for those that did, many questions arose regarding the experiences of those few patients that did live and were discharged. Thus, information obtained from this study may be pertinent and extremely helpful to the healthcare team in further treatment of these patients. The goal of this study was to gain a deeper understanding of the patient’s lived experience through cardiac arrest and therapeutic hypothermia lending insight for the healthcare team, especially those at the bedside, when making care decisions.

The second research activity of van Manen’s (1990) method involves investigating experience as we live it. This activity requires the researcher to stand “in the fullness of life” as well as to explore this subject of “lived experience through all its modalities and aspects” (p. 32). Being involved in the care of cardiac arrest patients with the initiation, maintenance, and termination of therapeutic hypothermia, this researcher is well oriented to the processes and themes of the experience from the caregiver aspect. Through guided interviewing, observation, and reflective listening, this research is aimed at understanding the lived experience from the patient’s perspective.

Reflecting on essential themes is the third research activity defined by van Manen (1990). This involved continuous reflection regarding that which is incomprehensible and bringing it into the light of consciousness. This researcher sought those themes that were common throughout the interview process and comprise the nature of this particular
lived experience. Identification and analysis of the discovered themes contribute to the care of these patients.

*The art of writing and rewriting* as the fourth research activity by van Manen (1990) challenges the researcher to eloquently, yet completely, articulate the lived experience of the participants. This is interpreted to mean not incorporating the researcher’s subjective opinions, but objective observations and not detracting from meaning but, instead, holding fast the integrity of the expression. Phenomenology is a “poetizing project” and that the writing should use “language that authentically speaks the world.” (van Manen, p. 13). This researcher reviewed the findings multiple times as well as the writings to make sure themes are well-articulated.

The fifth research activity described by van Manen (1990) is to *maintain a strong and oriented relation*. This can be “extraordinarily demanding” on the researcher as it is easy as well as tempting to change course mid-stream (p. 33). During this activity, van Manen demands that one must be “strong in our orientation” as to “not settle for superficialities and falsities.” (p. 33). The researcher must maintain focus and determination to adhere to the original research question, “be consumed by it.” (p. 153). To discover the answer to the research question and understand the experiences through the expression of the patient is the aim of this research.

The sixth and final research activity *balancing the research context by considering parts and whole* reminds the researcher that they must be committed to continuously challenging the structure of the study design and examining how the significance of the parts contribute to the substance of the overall study. “It is necessary to step back and look at the total….and how each of the parts needs to contribute toward
the total.” (p. 34). This is essential to ensure that the primary message being introduced by the research is being portrayed.

**Research Plan**

**Participant Selection**

Qualitative analysis often only uses a small sample size, continuing to recruit participants until saturation is achieved. Data saturation is reached when enough information has been obtained to replicate the study and achieve the same results (Fusch & Ness, 2015). Although samples are small, it “does not mean that qualitative researchers are unconcerned with quality of their samples” (Polit & Beck, 2014, p. 283). More does not necessarily mean better. The participants in this study were selected through convenience sampling. Convenience sampling is defined as recruiting participants who fit the inclusion criteria and will best contribute to the study based on their knowledge of the phenomenon under study (Polit & Beck, 2014). Because the number of potential participants is likely very limited due to the nature of the examined experience, this researcher is dependent on those who are willing to share their experiences to come forward.

After discharge from the hospital, many follow-up visits with an outpatient cardiologist usually results in an order for the patient to begin cardiac rehabilitation. This is where post arrest/therapeutic hypothermia patients were identified and recruited. Permission from the local area’s Cardiology departments was sought and granted to place flyers in the Cardiac Rehab departments and front offices. A flyer (Appendix C) explaining the details of the study was posted in areas visible to patients and contact information was included for those who were interested in participating in the research.
Data Generation and Analysis Procedures

Data Generation

Trust is the foundation of any relationship, no matter how involved. In qualitative research, the participant needs to know that the researcher is genuinely interested in the subject matter and wants to truly understand the experience from the participant’s point of view. A researcher with a solid background in the subject matter will have a simpler instance developing a rapport, mutual comfort and conversational ease (Bell, Fahmy, & Gordon, 2016), with participants because there will be a commonality between them. With rapport comes collaboration. This researcher has extensive experience in managing these patients within the critical care environment and can offer information to the participant that may not have otherwise been available. In turn, the participant can answer questions that are, also, not otherwise attainable. This exchange is relevant to build trust.

In-depth interviews are required when utilizing the qualitative phenomenological approach. Open-ended questions are used to encourage participants to “define the important dimensions of the phenomenon and to elaborate on what is relevant to them” (Polit & Beck, 2014). The researcher wants to create an environment that is conducive to genuine data generation without influencing the participant’s answers. A location that is most comfortable for the participant was chosen so that there was no hesitancy to share information based on surroundings.

Analysis Procedures

Qualitative research cannot be analyzed in the same fashion as quantitative research. In phenomenological research, van Manen (1990) suggests an approach with
three phases. The first phase is the holistic approach. This is done by going through all of the data and trying to find the “fundamental meaning of the whole” (p. 93). The second phase of the selective approach is finding certain phrases or statements that reflect the meaning of the experience being described. Finally, the detailed approach is going through the text, line-by-line, and asking what these sentences reveal about the phenomenon.

In conjunction with van Manen’s three phase approach to data analysis is Colaizzi’s 7-step strategy (as cited in Shosha, 2012). The steps include the following:

1. *Each transcript should be read and re-read to obtain a general sense about the whole content.* In conjunction with van Manen’s holistic stage of analysis, this allows the researcher to get very familiar with the content of the interview. Because a wealth of data can be gathered from these interviews, knowing the details is imperative to the analysis. Each audio recording was transcribed and read multiple times for analysis.

2. *For each transcript, significant statements that pertain to the phenomenon under study should be extracted.* While immersing oneself into the data, there are significant statements that arise and are written and coded separately for later analysis. This is very similar to van Manen’s selective reading approach. Any statements made by the participants that directly relate to the phenomenon under investigation is considered relevant (Edward & Welch, 2011).

3. *Meanings should be formulated from these significant statements.* Similar to van Manen’s (1990) detailed approach, the significant statements will be analyzed
further to garner the meaning of the participants’ spoken words. The researcher will ask “What does this statement reveal about the experience?” (p. 93).

4. The formulated meanings should be sorted into categories, clusters of themes, and themes. Common themes throughout each participant’s interview will be sorted into clusters and categories, giving the researcher some organization for interpretation. Some statements or themes that seem to stand alone will be placed into a category of their own.

5. The findings of the study should be integrated into an exhaustive description of the phenomenon under study. The researcher will provide a comprehensive explanation of the phenomenon while including the analyzed themes to provide and exhaustive description of the studied phenomenon.

6. The fundamental structure of the phenomenon should be described. Effort will be made on the part of the researcher to provide an intensive explanation synthesizing the generated data from the participants in order to create a clear idea of the phenomenon under study.

7. Finally, validation of the findings should be sought from the research participants to compare the researcher’s descriptive results with their experiences. The researcher will confer with the participants to compare the findings with the perspective of the participant. This will help to ensure trustworthiness.

Ensuring Trustworthiness

Unlike quantitative research, qualitative study has been questioned about its rigor. Guba (1981) presented four reliability checks that help the research community ensure
trustworthiness. These criteria include truth value, applicability, consistency, and neutrality.

Credibility, or truth value, can be achieved by taking the data back to the subjects for accuracy. This would be validating the data creating credibility. Applicability refers to the ability to apply the research findings to other populations in different contexts. Consistency refers to the auditability, such that other researchers can follow the study and come to the same or similar conclusions. Neutrality refers to the freedom from researcher bias.

Summary

In this chapter, the history of phenomenological research was discussed. The importance of using this methodology in qualitative research as well as van Manen’s and Colaizzi’s approaches to analysis was described. Finally, a brief discussion of trustworthiness in qualitative research was outlined.
CHAPTER IV

METHOD OF INQUIRY: APPLIED

Sample: Participant Recruitment and Selection

The method of sampling that was used for this research was that of a convenience, or volunteer, sample. Convenience sampling relies on people to “come forward and identify themselves” (Polit & Beck, 2014, p. 284). Flyers were posted in three different Cardiac Rehab programs in the area with permission from each facility’s research department and cardiology department managers. The goal was to interview up to 10 participants in hopes that data saturation would be achieved. Polit and Beck (2014) describe saturation as when, during the sampling process, no new information is received. Because of the uniqueness of the inclusion criteria, it was known that there would likely be few respondents.

The inclusion criteria included: the participant had to be over 18 years of age, had experienced a cardiac arrest outside of the hospital setting, achieved return of spontaneous circulation, and was treated with therapeutic hypothermia. Cardiac arrest survivors not treated with therapeutic hypothermia were excluded from the study. Three participants, who met inclusion criteria, stepped forward to share their experiences.

Participants agreed to meet with this researcher, face-to-face, in a place of their choosing as to maximize their comfort. In addition, they agreed to and verbalized understanding that the interview would be audio recorded then transcribed for the researcher to analyze later. Participants also agreed to follow-up communication to clarify any incomplete thoughts, agreement with themes, and the opportunity to offer any
additional information that the participant feels is important to share about their experience.

Gaining Access

Protection of Human Subjects

Approval of this qualitative research study was pursued and granted to this researcher by the Internal Review Board (IRB) of The University of Nevada, Reno (Appendix A and B). Approval from the facilities where the flyers were placed was also granted by the facility’s research department as well as the cardiology department managers.

Recruitment

Once approval was granted by the Internal Review Board and the facilities’ department managers, recruitment flyers (Appendix C) were placed in the cardiac rehab offices as well as the cardiology front offices. The flyer included contact information for this researcher as well as a brief description of the study’s purpose. Those interested were asked to contact this researcher so that an interview could be arranged. Upon contact, prospective participants were given a more in-depth description of the study and its purpose, the proposed recorded interview process, data transcription and analysis, and follow-up for confirmation of experience themes.

Privacy and Confidentiality

All information obtained through interviews with participants in this study is and will remain confidential. All recordings and transcriptions will be maintained in a locked cabinet, in the PI’s office for three years following completion.
Consent

Consent forms were given to all participants and benefits and risks of participation were explained. Consent was given verbally by all participants before the interview began. The consent form explained that participation was voluntary and that, if the participant decided to withdraw from the study, it could be done at any time and without penalty. Should they decide to withdraw from the study, any information previously obtained would be destroyed.

Data Generation and Analysis Procedures

Data Generation

Data for this study was collected by doing face-to-face interviews that were approximately one hour long. The interview was conducted in a mutually agreed upon place that offered the most comfort and privacy for the participant. Researcher prepared questions were utilized (Appendix D). The interview was recorded on a digital recording device, then transcribed by a professional transcriptionist and reviewed by this researcher for accuracy. Initial questions included demographic information to identify specific characteristics about the participants. Field notes were used to help the researcher remember the participants’ expressions that would not be discernable by recording.

Data Analysis

Data analysis began with listening to the recordings of the interviews and reading the transcriptions multiple times. Van Manen’s three techniques of analysis, the “wholistic” approach, the selective reading approach and the detailed reading approach, were used to begin data analysis. These techniques consisted of observing and listening to each participant, reading and rereading transcript texts, and searching for emergent
themes while reflecting on their meanings. Finally, Colaizzi’s (1978) seven step method further contributed to the quality of the emerging themes.

1. *Each transcript should be read and re-read in order to obtain a general sense about the whole content.* This researcher arranged and performed all participant interviews. Upon completion of the interviews, the researcher repeatedly listened to the recordings to begin analysis. Recordings were sent for transcription by a professional transcriptionist and product was reviewed for accuracy by the researcher. Transcripts were reviewed multiple times, as well as field notes, to gain a general sense of the ideas, thoughts and emotions displayed in the content.

2. *For each transcript, significant statements that pertain to the phenomenon under study should be extracted.* Through “wholistic”, selective, and detailed analysis, significant words, phrases and statements were developed. In attempt to categorize the information, this novice researcher coded all the information by hand using highlighting, underlining, and page-marking.

3. *Meanings should be formulated from these significant statements.* In this phase of analysis, this researcher began analyzing significant words, phrases and statements which were thought to be significant to the participants. A copious amount of time was taken to analyze this data and find which phrases were particularly meaningful. General meanings were developed from each statement and prepared for theme extraction.

4. *The formulated meanings should be sorted into categories, clusters of themes, and themes.* Examination of the data permits the researcher to gain a relationship with the participant’s experiences. Words, phrases and statements that are consistent
through all the interviews emerge and become themes. This researcher arranged
the themes into clusters and validated with original data.

5. *The findings of the study should be integrated into an exhaustive description of
the phenomenon under study.* This researcher aims to provide an exhaustive
description of the interpretation of the experience of cardiac arrest treated with
therapeutic hypothermia. The goal is to establish commonalities within the
examined experiences that may be applied to others who have the same
experience.

6. *The fundamental structure of the phenomenon should be described.* An effort was
made to integrate all the themes and theme clusters that had been discovered
through the interview process. This is the progression used to generate a
statement of recognition.

7. *Finally, a validation of the findings should be sought from the research
participants to compare the researcher’s descriptive results with their
experiences.* Research participants were contacted by telephone after analysis
was completed to compare thematic results to the participants’ perceived
experience. Colaizzi (1978) states that, to validate research results, the researcher
must go back to the participants to make sure that the discovered themes actually
reflect the experience of the participant. This also provided an opportunity for
participants to offer additional insights or details that are relevant to the
experience.
Ensuring Trustworthiness

Following Guba’s discipline in ensuring trustworthiness assisted this researcher in accomplishing the credibility of this study. Rigor and validity were achieved by using Guba’s (1981) four principles of truth value, applicability, consistency, and neutrality.

Truth Value

In this phenomenological analysis, this researcher used van Manen’s method of inquiry as he is highly respected in this field of study. Building rapport with the participants is also a very important component of truth quality. Encouraging the participants to speak freely and giving reassurance that the researcher would refrain from judgment helps to build rapport early on. This researcher has experience in recovery and management of cardiac arrest patients being treated with therapeutic hypothermia which gives participants belief that the researcher understands the process and genuinely is interested in their experiences. Each participant was given detailed information about the study and the interview process. They were informed that they could decide, at any time before or during the study, to withdraw participation with no consequences.

Applicability

Applicability refers to the ability of this study to pertain to other populations and offers external validity. The findings of this inquiry are specific to patients that have experienced a pre-hospital arrest and were treated with therapeutic hypothermia, which has a very small percentage of survivors. Though it may not be completely
transferable to other populations, this researcher feels that offering a rich and thick
description of this experience will offer valuable information for healthcare providers.

Consistency

To uphold consistency in this study, the processes used during this study are
described comprehensively. This researcher provides a thorough description of the
inquiry planning process, execution of the study, the particulars of the field
encounters, and the process of evaluating effectiveness. This ensures that methods
and findings can be followed and confirmed by readers and other researchers.

Neutrality

Neutrality means to imply that the inquiry is free from the personal bias of the
researcher. This researcher took various important steps to ensure that bias was
avoided as much as possible. Multiple discussions regarding researcher bias and
ways to confront and sidestep the issue were undergone. Although this researcher has
personal experience in managing cardiac arrest patients treated with therapeutic
hypothermia, nothing was known or assumed about the lived experiences of these
patients. With member checking, this researcher encourages feedback from
participants to ensure the correctness of the analysis on information (Polit & Beck,
2014).

Chapter Summary

In this chapter, van Manen’s approach to phenomenological inquiry and analysis
was revisited as it was applied. Also discussed were Colaizzi’s steps to analysis and
trustworthiness was ensured throughout data collection and analysis.
CHAPTER V
FINDINGS

The purpose of this phenomenological inquiry was to explore, describe and understand the meaning and significance of the lived experience of cardiac arrest patients that had been treated with therapeutic hypothermia. The question guiding this research was: What is the lived experience of pre-hospital arrest survivors treated with therapeutic hypothermia? The findings of this study will largely contribute to the revision of discharge planning for these patients as well as contributing to the guidelines for follow-up and patient education. The following stories come from people who lived through cardiac arrest, the gold-standard of hypothermia treatment, and were willing to share their experience to improve care experiences for others.

Description of the Participants

A total of three participants were recruited for this study. There were two women and one man whose ages ranged from 51 to 69 years. The male participant is married and the women are not married at the time of this writing. All participants had a witnessed arrest with CPR, being witnessed by a spouse or family member. Two out of three of the interviews included the person who was with the participant when the arrest happened.

Data Collection

All three interviews were conducted between April and June of 2016. None of the participants were known to the researcher and all were recruited through the Cardiac Rehab programs. The interviews were held in a private location that was chosen by the participant for their comfort. One interview was held in the participant’s home and the other two were held in a private seating area in a local library. All locations were
comfortable to the participant and researcher. Participants were situated in chairs across from the researcher and cell phones were silenced to avoid distraction. Coffee, tea, and snacks were offered to participants.

Participants were given consent forms for their review. Each was given approximately 10 minutes to review the consent and prepare any questions that they may have concerning the consent process or the study in general. The researcher answered any and all questions and was permitted to proceed with the interview. The participants were reminded that participation was voluntary and that participation may be withdrawn at any time.

To put the participant at ease and build a sense of rapport, an open dialog was held for approximately 10 to 15 minutes before the formal interview began. The researcher asked the participant if they were ready, and when the participant responded “yes”, the recording began. At the end of the interview, the participant was asked by the researcher “Is there anything else that you would like to share about your experience?” When the participant was clear that they had no other thoughts to share by saying “No.”, the recording was stopped.

The participants were contacted in October of 2016 to discuss the accuracy of the transcription of their interview. Contact was made through telephone conversation. These conversations were to clarify and confirm that they had answered the interview questions as they wanted to and that they didn’t have any more information to add. All three participants completed the study.
Data Analysis

All the digitally recorded interviews were transferred to compact disk and given
to the transcriptionist. In approximately 2 weeks, the transcripts were finished and
returned to the researcher along with the compact disks. The data were hand-coded by
the researcher using Colaizzi’s 7 step method as delineated below.

Immersion

Before the transcripts were completed, the researcher listened to the recorded
interviews thoroughly. Notes of any thoughts, feelings, or ideas that came forth during
listening to interviews were recorded in the field journal for further investigation by the
researcher. When the transcriptions were finished, the researcher read the verbatim text
while listening to the interview to ensure accuracy. The texts were read numerous times
to gain a complete sense of the participants’ experience. This process helped the
researcher to familiarize oneself or become immersed in the experience. Again, thoughts,
feeling and ideas gained by the researcher by reading the transcripts were noted in the
field journal.

Extraction of Significant Statements and Phrases

Each of the interviews produced between 25 and 39 pages of transcription with a
total of 33,276 words. Through hand coding done by the researcher, 164 significant
words, statements and/or phrases were identified that depicted the lived experience of
pre-hospital arrest survivors that were treated with therapeutic hypothermia. A word
document was created where these were organized and saved.
Formulation of Meanings

This researcher spent time to associate meaning to all the extracted words, statements and phrases. Every attempt was made to ensure that the meanings remained true to each participant’s original statements.

Organizing Clusters of Themes

The formulated meanings were examined and organized for similarity. From this organization process, theme clusters were fostered. Themes transpired from the clusters that represented the individual and group experiences of the pre-hospital arrest survivors that were treated with therapeutic hypothermia. Validation of this step was attained by returning to the original interviews to make sure that there were no omissions and all valuable information was accounted for.

It is important to acknowledge that, during the analysis, there were discrepancies and some contradictions noticed. This is a normal happening and the researcher must be tolerant of the obscurity (Colaizzi, 1978). Participants were contacted to verify the researcher’s interpretation of developing themes as a form of member-checking (Lincoln & Guba, 1981). The following statements were made by the participants during the validation process about how they confirmed the findings.

That sounds about right. (Anne)

That’s very interesting! I have nothing more to add. (Bill)

Weird. Cool, but weird. I think that covers it. (Jennifer)

Returning to the participants for validation allows the researcher confidence that the interpretation of the analysis and theme development was accurate for the experience under investigation.
Essence, Themes and Subthemes

Despite aggressive recruitment attempts, only three participants volunteered for this study. This was expected by the researcher as the experience itself yields a small percentage of survivors. The following information provided, are the similarities in their stories. The qualitative terms of themes and subthemes are used to exhibit those similarities in the participants’ experiences.

This researcher identified five themes that reveal the lived experience of the prehospital arrest survivor that was treated with therapeutic hypothermia. These themes are (1) lost time (2) urgency to leave hospital setting (3) physical changes (4) lack of advance directives and (5) acknowledgement of own death. Four of the five themes are further divided into subthemes that offer a deeper explanation of the experience. Compilation of these themes and subthemes contribute to a more thorough understanding of the participants’ lived experience.

Theme: Lost Time

This main theme appeared in all three interviews and one of the biggest initial challenges for the participants. From the day of the arrest to just before discharge, the participant has no memory. This led to the three subthemes (1) clear memory to no memory (2) first post-arrest memories and (3) remembering with the memories of others.

Subtheme: Clear Memory to No Memory. This theme emerged when asked to talk about the day of their arrest. The following statements reveal this theme as a very integral part of their experience and sets up the emergence of themes discussed later.

I’m gonna let my sister tell you because I don’t remember. I spent the weekend (before) in Tahoe with my sisters and my brother and I kind of remember that… (Jennifer)
I just remember we went to the gym. I do know we were at the gym and, uh, I do remember starting abs, but from that point on, no don’t remember anything. (Bill)

I went to her (daughter’s) house and we had dinner and then we went for a walk. She lives out right next to the forest so we went on a trail… in a well-known area up there in Tahoe. And um on the way back I did fine, you know went through the whole thing… but all of the sudden I told her I’m short of breath. I don’t know if I was just short of breath or dizzy. But that’s the point from there on I don’t remember. (Anne)

**Subtheme: First Post-Arrest Memories.** This theme presented itself when the participants were asked if they remember anything about their in-patient treatment. It also represents the time lost between pre and post arrest memory.

So, um, I had no idea what happened. It was a week later. And that’s my earliest memory, being frustrated that this damn thing (endotracheal tube) was in my throat. I couldn’t talk, but also having no idea, and they all kept saying we would talk about it in a little bit. (Jennifer)

Nothing. I don’t remember waking up. I remember coming home. (Bill)

I didn’t really have a memory until, I think, like 10 days later when I woke up to me anyway. (Anne)

**Subtheme: Remembering with the Memories of Others.** This subtheme is substantial in that it is the only way that the participants know what happened to them when they arrested and during the acute phase of recovery.

Monday night (the night of the event) we went out to dinner at one of our favorite restaurants where we go all the time but as far as any memory of that weekend, no. I mean, I kind of remember that, but I think it’s more because of the pictures they showed me… (Jennifer)

I was doing abs on the ab machine and (wife) looked up and saw me as I was getting off the ab machine and she said is something wrong. I believe I nodded to her and said yes there was and she asked me if she should call 911 and I said yes. And she put me down on the floor, she yelled at the people at the gym to call 911 I believe… I guess (wife) could tell it better since she was there… (Bill)

I sat down indian-style she said but I immediately fell back and hit my head pretty hard on a rock. She did what she could. Luckily there was another man that
was right there. He called 911 and, um, I think it was like, she doesn’t know but, 4-8 minutes later when the sheriff showed up to do CPR. She said I died in her arms… Basically, I got told what happened to me then got sent home two days later. (Anne)

Interestingly, even after the participants were awake and alert, much of the memory while still hospitalized and first at home is lost only to be explained to them by family members.

They told me that I was being myself, cracking jokes and being a smart ass. They would tell me stuff and I wouldn’t remember the next day, like I had never heard the story before. I couldn’t even remember where my son was going to college. (Jennifer)

When I woke up, they tell me I was an ass. My wife tells the story about me telling a story about having really good cutlery. My sister was here and I was telling her how sharp my knives were and running my fingers across them. That’s how not aware I was. I would have conversations and have no recall of those. (Bill)

I mean I woke up before that. I was actually talking to people and stuff, but I wasn’t aware of it. I was being my normal self and they were talking to me, they didn’t realize I wasn’t remembering. (Anne)

**Theme Summary**

This theme and its subthemes demonstrate how these participants experience a period of time that they have no recollection of. From the time of their arrest to the time that they begin remembering again, they are forced to relive that gap in time through the memories of those who were present for the event and the acute phase of recovery.

**Theme: Urgency to Leave the Hospital**

Another common theme among the participants was the sense of urgency to get home as soon as they could. All the participants verbalized that they thought of themselves as very independent people and that they believed they were ready to take
care of themselves. They confessed that they didn’t appreciate the gravity of their situation initially.

I just wanted to get out of there and go home. I felt fine. It seemed like I recovered so quickly. I almost had to tell them to let me do it myself. I wanted to be more independent and was really antsy to get out of the hospital. I just wanted to go, please. When I finally got home, I was afraid. I realized that I was safe in the hospital. (Jennifer)

I demanded to go home, which they probably shouldn’t have let me go but I guess they told (wife) that if I did say I wanted out they had no choice but to send me home. Uh, or I was being an ass enough that they wanted me to go home. But even when I got home I wasn’t cognizant. But cognizant enough to figure out what to do and how to do things physically. As soon as they let me walk, I never slowed down. I wanted to go home. I got home and started planning to pour concrete in my driveway. I was hyperactive. It wasn’t until my wife called my primary doctor and he told me to slow down. Then I did. (Bill)

I was a little rebellious because I thought I could walk to the bathroom by myself once I was awake. I left there feeling good. I don’t think it had sunk in what really happened. I didn’t understand the seriousness of it all. (Anne)

**Theme Summary**

This theme describes the participants’ urgent sense of wanting to leave the hospital. They acknowledged that, once they were home, they were not as well as they initially believed.

**Theme: Physical Changes**

This theme is present in all interviews and depicts the participants’ recognition of physical changes during and after their hospital experience. They didn’t remember their arrest or much of their treatment so recognizing and understanding their limitations was challenging. Two subthemes were recognized here as (1) hospital changes and (2) recovery and lingering sequelae.
**Subtheme: Hospital Changes**

I was weak…my hands were bloated and my head was all banged up. I thought I could walk to the bathroom by myself… (Jennifer)

I felt I healed up quickly, I didn’t realize that I needed to slow down. I thought I was capable of doing everything. I was refusing to take my medications and use my oxygen until my primary doctor put me in my place. (Bill)

My calves were one-third the size. Everything was so atrophied. When I saw the way everything looked I was like oh my God, you know. I’m teeny but I’m not that teeny. I was wearing oxygen all the time and I didn’t like it at all. (Anne)

**Subtheme: Recovery and Lingering Sequelae**

I feel like I recovered quickly. The only thing is that I used to be hot all the time, but now I’m cold all the time. (Jennifer)

I felt like I recovered well. I do accept the fact that it could have been that I just didn’t pay much attention before, but ah the colors are vivid, I mean vivid, vivid to me… oh we went to the lake and ah the pine trees and whatnot, it is like a kaleidoscope to me anymore. I’d never experienced that before in my life. It is very enjoyable. Awe inspiring as a matter of fact. (Bill)

My oxygen gets low at night. They wanted me on oxygen full time when I got home but now I only wear it at night. They told me that my body forgets to breathe sometimes. But I manage to stay busy and I recovered fast, I think. (Anne).

**Theme Summary**

The participants had to deal with their new bodies and recognize that they needed to make modifications in their lifestyles. It was difficult because they all describe themselves as independent and weren’t comfortable relying on others for help.

**Theme: Lack of Advance Directives**

Despite having had cardiac arrest, none of the participants had developed a plan if anything life-threatening were to ever happen again. This theme developed when the participants were asked if they now had an advance directive.

No, but we’ve been talking about it. I’m registered to learn CPR though! Maybe I can pay it forward. (Jennifer)
No, we don’t and we keep saying we need to do that and we have not. I’m afraid to do it. Because if I had had it, what if they said don’t bring him back? (Bill)

No I haven’t and I need to. But the kids all know that um I don’t want to be resuscitated it it’s… you know. (Anne)

**Theme Summary**

Though all the participants lived despite cardiac arrest, they have not established an advance directive. They all state that they have discussed it with their families.

**Theme: Acknowledgment of Own Death**

During the interview process, the idea of one dying came up with all three participants. Two subthemes of this main theme are identified as: (1) incomprehension and (2) acceptance and reverence for life.

**Subtheme: Incomprehension.** This theme describes how the participants felt when they found out what had happened to them.

The whole experience was surreal… unreal… crazy. I died. I couldn’t believe it. I totally thought they were joking. I kept saying ‘shut up’. I couldn’t believe it because I felt fine. It didn’t make sense to me. The whole thing didn’t make sense to me. It would’ve made more sense if I had been in a car accident. Reality hit and I cried and cried, especially when I got home I was really emotional. I would cry myself to sleep. It was too big to wrap my head around. (Jennifer)

I started to deal with questions about what if it had happened somewhere else or what if my wife wasn’t there. I wouldn’t be here. I realize that after a week I finally came to the conclusion that I died. It’s pretty hard to explain thinking of - have knowledge that you actually died. Why did I come back? I get to think about that. People that die don’t get to think about that. (Bill)

I was blown away. I died. I was following all the rules, most people thought I had the healthiest diet of anyone we knew. I tried to work it out in my brain and we came up with perfect storm. (Anne).

**Subtheme: Reverence for Life.** This subtheme was revealed in all three interviews about how the participants felt after being able to comprehend their experience.
I’m always aware of it. I think I’m a little less to take life for granted. It really makes you stop and ask why. I almost feel like there’s a responsibility with that. I realize that life is short and you need to enjoy it and do what you want to do and do what feels right, you know? (Jennifer)

I look at everyday today being grateful that I’m here. Every day I think I could’ve been gone. We appreciate every moment we have. I’m glad to be alive. I live my life now with no regrets. I’m doing exactly what I feel and we do the things we want to do. Don’t be afraid to die. It’s not terrifying. Except for the one who’s awake looking at it. I don’t imagine I could say it’s pleasant, but what happens after you’re gone whether there’s lights or people there you meet or you have an out-of-body experience, I will leave up to each individual to experience. I am not afraid. (Bill)

I don’t worry about whether I’m going to die tomorrow or in 20 years. But it has made me seize the moments a little more, or if I’m feeling down and a friend calls me and wants to do something, I make myself go do it. So, I think it’s made me a little more proactive. I am thankful that I lived and for the little things that happen and I’ll say thank you. The universe talks to you. Even if it’s a green light that shouldn’t have stayed green. Sooner or later, I’ll find out why I survived. (Anne)

**Theme Summary**

This theme and its subthemes address how the participants dealt with the reality of their own death. It involves their initial reactions, how they have come to terms with it (dying) and how it’s changed their perspective on life.

**Chapter Summary**

The lived experience of pre-hospital arrest survivors who were treated with therapeutic hypothermia was explained though five themes and five subthemes that were discovered through analysis of the data from their interviews. Each theme and subtheme contributed to the overall essence of the participants’ experience with sudden cardiac death and the unlikely recovery.
CHAPTER VI

DISCUSSION AND INTERPRETATION

The purpose of this phenomenological inquiry was to explore, describe, interpret and gain a deeper understanding of the lived experiences of cardiac arrest survivors, specifically those who were treated with therapeutic hypothermia following their arrest. In this research, five themes were identified with five subthemes from each participant’s fascinating story.

As each participant shared their experience, common themes emerged associating each one’s experience together. Although their experiences were unique, a common thread of uncertainty was woven through their stories. The themes that surfaced became fundamental to understanding their experiences. The full and powerful descriptions offer insight into the experience of those who have lived through cardiac arrest and were treated with therapeutic hypothermia.

Findings as They Relate to the Current Literature

The focus of current literature, in qualitative research, is that of cardiac arrest survivors that regained consciousness with the return of spontaneous circulation (ROSC). Therefore, they were not candidates for therapeutic hypothermia. There is paucity in the literature solely focused on cardiac arrest survivors that remained unconscious after ROSC and were then treated with therapeutic hypothermia in attempt to save the brain. Considering this, the findings of this phenomenological study are compared to what is currently available in the reviewed literature.
Participant Demographics

A total of three participants were recruited for this study, two women and one man. Their ages ranged from 51 to 69. The gentleman is married and both women were single at the time of this study. The recovery path at the time of this interview ranged from 3 months to 3 years. All participants had a witnessed arrest while with a family member or significant other.

Main Theme: Loss of Time (Subthemes: Clear Memory to No Memory, Time Passes then Memories Begin, and Living through Other’s Memories)

The findings of this study show how the participants’ all experienced a loss of time during their arrest and treatment phase. From some time before their arrest to hospital discharge or after, these patients lost up to 10 days of time. Forslund, et al. (2014) discuss how many cardiac arrest survivors had fragmented memories of the time before and after the arrest. Although the participants were aware that they weren’t feeling well at the time of their arrest, they were unaware that they were about to experience a potentially lethal medical problem. One participant from this study, Jennifer, had even lost memory of the entire weekend before her event that happened on a Monday.

The Forslund et al (2014) study also discusses how these survivors needed to be filled in on what had happened during the time of their missing memory. They were forced to live through the memories of their family members and/or spouses and still communicate with their loved-ones about what happened during that time. Similar experiences were noted from the participants of this current study; Jennifer did not believe that she had a cardiac arrest and thought she must have been in a car accident.
Another study conducted with out-of-hospital cardiac arrest patients discussed that the loss of memory these patients experienced became a memory in itself and encompassed its own significance when considering the event (Bremer, Dahlberg, & Sandman, 2009). Again, similar findings were identified in the current study; the participants allowed the person who was present for the arrest tell the story of the arrest as it happened and listened as if they were waiting for new details. Jennifer was still asking questions as her arrest was only three months prior to this interview. Anne and Bill were better able to help with the story line yet still asked questions about specifics.

An additional thought that contributes to the loss of memory could be related to the sedation medications that are used when a patient is comatose, and going through hypothermia and rewarming phases. The intention of these medications is to help the patient be comfortable during this process. Unfortunately, studies have found that even during the critical neurological examination period, sedating medications are still given confounding or even nullifying the results of the exam for the patients who are still comatose which can alter the plan of care tremendously (Beseda, Smith, & Veenstra, 2014; Samaniego, Mlynash, Caulfield, Eyngorn, & Wijman, 2011).

**Main Theme: Urgency to Leave the Hospital**

In an article published in 2012, Onukwuhga et al. describes patients wanting their own physician, to be involved in their own care, the length of waiting time, and factors outside of the hospital as being motivation for patients in a cardiology setting leaving against medical advice. The findings in this current study revealed that all three participants experienced an urgency to leave the hospital. Mostly, they were unsure with where this urgency originated from, though all three participants described feeling this.
The participants in this study did not infer any of these ideas nor were they able to articulate any reason for their urgency to leave the hospital. One might speculate that this urgency was related to their perceived level of independence, their inability to accept their circumstances, and having to depend on someone else for their care as these were areas that were discussed. Also, having to mentally and emotionally process their almost fatal experience may cause anxiety and the desire to be in a perceived safe place. The attempt to control their environment is actually a coping mechanism for anxiety (Robinson, Smith & Segal, 2017).

**Main Theme: Physical Changes**

The findings of this study show that the participants had less than expected physical limitations after their hospital discharge. One participant of this qualitative study discusses newly diagnosed central sleep apnea and her need for oxygen while sleeping while the one only discuss trivial changes that do not negatively affect her quality of life. Another participant admits that his new gift of being able to see colors more vividly could possibly be a positive contribution to his outlook on life.

Although this was thought to be an unexpected finding, a previous quantitative study published in 2015 followed 644 out-of-hospital cardiac arrest survivors and found that many of these survivors have no, mild, or moderate physical impairment after recovery and did not consider their quality of life to be dramatically affected (Nichol et al., 2015).

**Main Theme: Lack of End of Life Planning**

The findings of this study uncover that the participants, though having lived through a potentially fatal acute disease process, have not taken steps toward securing an
advanced directive, living will or end of life planning since recovery. All of the participants stated that they plan on it at some point; thought it was a good idea, but have not had it done. One participant stated that having an advanced directive made him scared because, if he had had one prior to his event, resuscitation may not have been attempted. This thought indicates that there is a knowledge deficit related to what he could have outlined in his advanced directive if he had one. This patient’s significant other stated that, during the rewarming process, she was afraid that she made the wrong decision by attempting resuscitation because she didn’t think he would want to live impaired if he lived and that he would be angry with her if he ended up in that state of permanent physical dependence or mental disability. Although many survivors agree that having an advance directive is very important, those that had it before they arrested did not make any changes to their directives post event (Lau et al., 2010).

A study published in 2014 observed that although most cardiac arrest patients did not have advanced directives, the advance directives that some patients had were not used in the care process to make decisions regarding withdrawal of care (Albaeni, Chandra-Strobos, Vaidya, & Shaker, 2014). These same authors noted that care was withdrawn on more than fifty percent of cardiac arrest patients and often before the accepted neurological awakening time. These statements paint a picture of irrelevance for the advance directive in the setting of cardiac arrest victims. However, this does not reduce the importance of such directive and family members’ knowledge of them.
Main Theme: Acknowledgement of One’s Own death: (subthemes: Incomprehension, and Reverence for Life)

At first, none of the participants could understand what happened to them. Grasping the fact that “I died” was very challenging and emotional. After being afforded the time to seemingly cope with their experience, all three participants feel grateful that they are still alive.

The participants for this study congruently felt that they didn’t quite grasp what had happened to them; even when explained by family members, they were in a state of disbelief. One participant in this study discussed how he always wondered if the outcome would’ve been different if he weren’t in that place with his wife. Palacios-Cena, Losa-Iglesias, Salvadores-Fuentes, and Fernandez-de-las-Penas (2011) discuss the feeling of “I actually died” as trying to grasp at meaning and not being able to find it. Additionally, Forslund et al. (2014) identify that many survivors will think about what would’ve happened if there were slightly different circumstances.

At the time of the interviews, all three of the participants stated that they were grateful that they could live and were going to live their lives without fear. One participant verbalized that he will take any chance he gets to do something he wants to do.

Many people that have had near death experiences come away permanently changed and many without fear of death (Cant, Cooper, & Chung, & O’Connor, 2012; Lommel, 2011). In the survivor’s experience, death was not hard, dramatic or scary (Forslund et al., 2014). These feelings were shared by sudden cardiac arrest survivors in the Palacios-Cena, et al. (2011) study. Their study describes a coping mechanism of
“onward and forward” which describes the sentiment of going on with life and enjoying the time that is left.

**Implications for Health Care**

The findings in the phenomenological study provide significant information for the medical providers caring for pre-hospital cardiac arrest survivors treated with therapeutic hypothermia. By discovering their lived experiences surrounding the event, medical providers can be better prepared for the follow-up that many of these patients may need.

In the theme of “loss of time”, participants describe having no recollection of their event and much of their hospital stay. This brings to light that perhaps much of the education that is conferred to the patient is lost. This highlights the importance of having family members and/or caregivers at the bedside as much as possible as well as having them present for any education that the patient receives. This can be done by making appointments with family members to be at the bedside during certain windows of time for education and discussion. Discharge education is of high importance and should involve a family member/caregiver so that the correct direction can be taken after release from care.

While these patients describe an urgency to leave the hospital, none of them are able to verbalize reasoning. A previously mentioned study by Onukwuha et al. (2012) suggests that these feelings may come from a lack of involvement in their care. It is important to remember that many of these patients may not have a deep understanding of the human body, the disease process nor the treatments that they are receiving. Keeping patients and families informed and answering their questions when they arise can help to
ease their feeling of urgently wanting to leave and may make the hospital experience less frightening for them and their families.

Some of the physical changes that cardiac arrest/hypothermia patients experience will be permanent. However, the atrophy that is experienced from being in a bed can be negated by early mobility. Several factors exist for not mobilizing intensive care patients, such as staffing shortages, cost, and invasive monitoring (Morris & Herridge, 2007). However, the risk to the patient from being bedridden is substantial and research shows that early mobility improves outcomes in hospitalized patients (Morris et al., 2011). Muscular weakness and denervation can make recovery far more challenging than recovering from illness alone. As described by Morris & Herridge (2007), the United Kingdom has been implementing post ICU follow-up clinics for more than 20 years with great success in illuminating the importance of long term follow up for this patient population. Many cardiac arrest/hypothermia survivors spend days in bed while only being turned to avoid skin breakdown. Early mobility and long term follow-up can help to mitigate some of the long term physical effects that could be treated or even prevented.

In this study, it was discovered that none of the participants had done any advanced planning prior to or after their cardiac arrest and treatment, though they stated that they had planned on it. In two separate studies of cardiac arrest patients, those who had done advanced planning felt that their wishes were carried out. As well, those who preferred not to be resuscitated had their wishes honored (Albaeni et al., 2014; Richardson, Fromme, Zive, Fu, & Newgard, 2014). The patients who had advanced planning and lived were thankful that they had them and advised friends and families to do so as well. Advanced planning is important for many reasons. Peace of mind is
 foremost for the patient. These documents (POLST, living will, durable power of
taxattorney) can give the patient confidence that, should they ever be in a life-threatening
experience/illness, their wishes will be carried out and their dignity maintained. Patients
having advanced planning can also help reduce health care costs around the world. In
2004, sixteen percent of the Gross Domestic Product (GDR) was spent for healthcare
costs with little evidence of benefit (Wendel, O’Donohue, & Serratt, 2014). Follow-up
after hospital discharge should include education regarding advanced planning for all patients.

When one is left to acknowledge that they had died and been resuscitated, likely
there are many questions left unanswered. Some of those questions can be answered by
medical providers, some can be answered by psychoanalysis and self-reflection, and
others may never be answered. The nature of the bedside care and the follow-up after
discharge can help these patients better cope with their experience. Offering local and
web-based resources for support can be a critical component to the psychosocial well-
being of the patient and their families. There are numerous web-based organizations,
such as the Sudden Cardiac Arrest Association, Sudden Cardiac Arrest Foundation, and
Mended Hearts that offer a variety of resources for emotional and physical concerns as
well a depression related to the cardiac arrest experience. Having a list of resources for
patients and families to take home may help them feel more empowered as they begin to
pick up the pieces of their lives. This could be an effective part of the discharge or the
follow-up after discharge to help address the psychosocial aspects of recovery.

All of the themes identified in this phenomenological study suggest that post-
discharge follow-up can be incredibly helpful in the recovery process. Helping patients
and families feel more informed about the process, retain critical education, and recover from the emotional as well as physical aspects of their incredible experience may increase the overall well-being of these survivors. Also, helping them to better prepare for future illness with advanced planning is crucial for peace of mind.

**Limitations**

Findings from this study are limited to one geographical area within the United States. While diversity was sought, all participants were Caucasian. The ability to recruit participants in this specific population proved to be difficult. Although there were themes that emerged from the interviews that all three participants identified, it cannot be said that data saturation was achieved.

**Recommendations for Further Research**

Recommendations for long-term and/or extensive follow-up have been made in this study. This researcher believes it would be beneficial to research the effects of long-term/extensive follow-up for cardiac arrest/hypothermia patients. To acquire findings related to a post cardiac arrest follow-up clinic would be beneficial to patients, families, medical providers, and possibly, insurance companies. Perhaps cardiac arrest patients who develop heart failure could be better managed therefore having less hospital admissions. In addition, the patients in this population who develop depression would have better access to resources for support. Finally, these patients could be educated about advanced planning and understand what it entails and have control over what will be best for them. This is an area that may help truly care for this population.
Chapter Summary

This chapter discusses the themes uncovered in this study and how the findings relate to other studies. The implications for healthcare imply that more can be done to support these patients after their discharge and return to life. Research in the direction of long-term follow up for this population was suggested with the understanding that more can be done to heal these people fully.
Conclusion

Three individuals who survived pre-hospital arrest and were treated with therapeutic hypothermia voluntarily participated in this phenomenological inquiry. The findings of this research yielded five themes and five subthemes which provide a thick, rich description of the lived experience of these participants. Findings were validated through participant review and provide the inclusive interpretation of these survivors. Understanding the meaning and experience of those who have survived cardiac arrest and were treated with therapeutic hypothermia provides benefit to healthcare providers and future patients who have this experience. This research contributes to a needed body of research concerning these survivors. Lastly, this research offers a single interpretation of this phenomenon and offers suggestion for avenues of future research.
APPENDIX A
IRB LETTER OF APPROVAL

| DATE:       | February 4, 2016                |
| TO:         | Stephanie DeBoor, PhD, APRN, CCRN |
| FROM:       | University of Nevada, Reno Institutional Review Board (IRB) |
| PROJECT TITLE: | [827266-1] The Lived Experiences of Pre-Hospital Cardiac Arrest Survivors Treated with Therapeutic Hypothermia |
| REFERENCE #: |                                          |
| SUBMISSION TYPE: | New Project                        |
| ACTION:     | APPROVED                           |
| APPROVAL DATE: | February 4, 2016                  |
| EXPIRATION DATE: | February 4, 2017                  |
| REVIEW TYPE: | Expedited Review                   |
| REVIEW CATEGORY: | Expedited review # 2               |

The above-referenced protocol was reviewed and approved by the UNR IRB in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46 and 21 CFR 50 and 55). This approval is based on assessment that the research met all applicable regulatory criteria. The research must be conducted in accordance with this approved submission. This submission has received Expedited Review based on applicable federal regulations.

Please prepare your continuing review form at least 4 weeks prior to your expiration date using IRBNet. Visit [https://www.irbnet.org](https://www.irbnet.org). Our office will send you a courtesy reminder to that effect. Unless renewed, the IRB only has authority under the federal regulations to allow a study to be open 12 months or less. There is no grace period. The study will be closed on the above stated expiration date unless the IRB receives and approves a continuing review report.

Instructions on preparing a modification or submitting your renewal is located on our web site at [http://www.unr.edu/research-integrity/human-research/irbnet](http://www.unr.edu/research-integrity/human-research/irbnet). Call our office if you have any questions or problems with use of IRBNet software.

**Approved Documents**

- Advertisement - Therapeutic Hypothermia Patients poster.pptx (UPDATED: 01/21/2016)
- Application Form - IRB app.docx (UPDATED: 01/21/2016)
- Waiver of Consent Form-Waiver (UPDATED: 02/04/2016)
- Consent Form - IRB information sheet (UPDATED: 01/21/2016)
- Questionnaire/Survey - Interview Questions (UPDATED: 01/20/2016)
- University of Nevada, Reno - Part I, Cover Sheet - University of Nevada, Reno - Part I, Cover Sheet (UPDATED: 02/3/2016)

If you have any questions, please contact Nancy Moody at 775.327.2367 or at nmoody@unr.edu.

**NOTE for VA Researchers:** You are not approved to begin this research until you receive an approval letter from the VASNHCS Associate Chief of Staff for Research stating that your research has been approved by the Research and Development Committee.
Sincerely,

Richard Bjur, PhD  
Co-Chair, UNR IRB  
University of Nevada Reno

Janet Usinger, PhD  
Co-Chair, UNR IRB  
University of Nevada Reno

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Nevada, Reno IRB's record.
APPENDIX B

STUDY DESCRIPTION

UNIVERSITY OF NEVADA, RENO INSTITUTIONAL REVIEW BOARD

TITLE OF STUDY:

INVESTIGATOR(S): Stephanie DeBoor, PhD, APRN, CCRN 775-682-7156; Melanie Hammond Perl, RN BSN, Primary Investigator (775) 303-1834

PURPOSE

You have been asked to participate in a research study. The purpose of this study is to achieve a better understanding of what individuals experience after living through cardiac arrest and being treated with therapeutic hypothermia. Understanding your experience might help healthcare providers to better support and care for those with similar experiences.

PARTICIPANTS

You are being asked to participate because you: 1) are 18 or older, 2) are English speaking, 3) reside in Nevada, 4) have experienced pre-hospital cardiac arrest, 5) were treated with therapeutic hypothermia following arrest.

Approximately 1-10 participant(s) will be enrolled in this study.

PROCEDURES

If you volunteer to participate in this research study, you will be asked to take part in a face-to-face, audio-taped interview, with the student researcher, lasting approximately one to two hours. The interview will be held at a mutually agreed upon, convenient location. This location will be private to ensure confidentiality of the participant and the information collected. During the interview you will be asked questions related to your experiences following pre-hospital arrest and therapeutic hypothermia. Following the initial interview, you will be asked to read the transcript from the interview and the student researcher’s interpretation to make sure it is a good description of your experience. Follow-up communication will be conducted either by telephone, post office mail or face-to-face. Review and discussion of the transcript is expected to take no more than one additional hour of your time. It is important for you to remember that your participation in this study is voluntary and all information shared will be kept confidential.

DISCOMFORTS, INCONVIENIENTS, AND/OR RISKS

There are risks involved in all research studies. This study may include only minimal risks. There may be some discomfort answering questions related to caring for one with a spinal cord injury. You may take a break, refuse to answer any question that makes you feel uncomfortable, or end the interview. You may withdraw from the study at any time. There are no risks for refusing to participate.
BENEFITS
You may not experience any direct benefits from participating in this study other than the satisfaction of having participated in research. However, we hope that learning about your experiences following cardiac arrest and therapeutic hypothermia will help health care providers to better understand how to manage and care for patients with similar experiences.

CONFIDENTIALITY
All information gathered during this research study will be kept completely confidential. All participants will be given an alias (pseudonym) to keep all material confidential. In field notes, recordings, and transcription, participants will be referred to by their pseudonym to protect anonymity and confidentiality of shared information. Interviews will be audio taped and transcribed by a private, professional transcriptionist who has signed a confidentiality statement. Your identity will be protected to the extent allowed by law. You will not be personally identified in any reports or publications that may result from this study.

The Department of Health and Human Service (HHS), other federal agencies as necessary, the University of Nevada, Reno Social Behavioral Institutional Review Board may inspect your study records. The study records will be securely stored in a locked file cabinet in the researcher’s office and destroyed in accordance with the granting IRB specifications.

COSTS/COMPENSATION
There will be no cost to you nor will you be compensated for participating in this research study.

DISCLOSURE OF FINANCIAL INTERESTS
The researcher has no financial interest in this study.

RIGHT TO REFUSE OR WITHDRAW
You may refuse to participate or withdraw from the study at any time without any risks or penalties to you. If the study design or use of the data is to be changed, you will be so informed and your consent re-obtained. You will be told of any significant new findings developed during the course of this study, which may relate to your willingness to continue participation.

QUESTIONS
If you have questions about this study or wish to report a research-related injury, please contact Melanie Hammond Perl, RN, BSN at 775-303-1834 or Dr. Stephanie DeBoor, PhD, APRN, CCRN at 775-682-7156 at any time.
You may ask about your rights as a research subject or you may report (anonymously if you so choose) any comments, concerns, or complaints to the University of Nevada, Reno Biomedical Institutional Review Board, telephone number (775) 327-2368, or by addressing a letter to the Chair of the Board, c/o UNR Office of Human Research Protection, 205 Ross Hall / 331, University of Nevada, Reno, Reno, Nevada, 89557.
Therapeutic Hypothermia Patients

My name is Melanie Hammond Perl and I am a Masters’ student at the University of Nevada. I am currently doing research about patients who have experienced cardiac arrest and were treated with therapeutic hypothermia.

I would love to hear your story!

Participants will have to agree to face-to-face, audio-recorded interview to be conducted in a private location that is convenient for you.

A follow-up meeting will be used to clarify any errors of the verbatim transcription, misinterpretations of researcher regarded themes, and allow participants an opportunity to add any additional thoughts about the lived experience.

Total time: Approximately 2 hours.

I hope you will choose to be a part of this research! Please contact me if you are interested.

mpperl@nevada.unr.edu
775-303-1834
This is NOT a Renown Sponsored Study
APPENDIX D
RESEARCH QUESTIONS

Research Questions

1. Tell me about the day you arrested. Who was there? Where did it happen? What do you remember?

2. Do you remember anything about being treated with hypothermia? Your hospital experience? What stands out?

3. What was it like for you when you first returned home from the hospital? How did you feel about it?

4. What is life like for you now? Do you have advance directives? Any chronic health issues as a result of arrest/hypothermia?

5. When reflecting on that whole experience, how does it affect your current outlook on life?
References

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http://cpr.heart.org/AHAEC/CPRAndECC/General/UCM_477263_Cardiac-Arrest-Statistics.jsp


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